

**Moral Dilemmas and Gender Scripts in the Context of  
HIV/AIDS  
A Qualitative Study among Ethiopian Women Living with  
HIV/ AIDS**

**Thesis submitted in partial fulfilment of Master of Philosophy Degree in  
International Community Health**



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### **Abbreviations**

HIV	Human Immuno- Deficiency Virus
AIDS	Acquired Immuno- Deficiency syndrome
UNAIDS	United Nations AIDS Program
WHO	World Health Organization
STI	Sexually Transmitted Infections
MTCT	Mother to Child Transmission
DHS	Demographic Health Survey
PLWHA	People Living with HIV/AIDS

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# Chapter I

## 1.1 Background

The HIV/AIDS pandemic, fuelled by a number of broader political cultural and social factors, affects lives of millions of people and cripples the economy of countries. According to UNAIDS/WHO AIDS Epidemic Update Report about 40 million people are living with HIV/AIDS globally and over 70% of the total HIV positive population in the world live in Africa. In sub-Saharan Africa, 28 million people live with HIV/AIDS and approximately 3-3.4 million new infections occurred in 2003 (1).

In the early stages of the epidemic, infection was predominantly among men. The trend has shifted and the number of infected women has grown steadily over the past years (2). The change in the trend is not, however, uniform universally and close to three fourth of all infected women live in Africa. In the worst affected region, Sub Saharan Africa, women account for 58% of the HIV infected population (2). More alarmingly, young women are becoming infected at a younger age than men and are estimated to comprise 67% of all newly infected 15-24 year olds (1, 2).

Ethiopia is among the hardest hit countries by the epidemic. The epidemic in Ethiopia is described as generalised among the overall population and the national adult HIV prevalence is estimated to be 6.6 percent (3). The earliest evidence of HIV infection was found in Ethiopia in 1984 with the first case reported in 1986. About 91 percent of HIV infections in Ethiopia occur among adults aged 15-49 and the highest prevalence is seen in the 15-24 age groups (3). According to UNAIDS, there are estimated 3 million adults living with HIV/AIDS and 990,000 AIDS orphans in the country.

Of the estimated three million people living with HIV/AIDS, 1.9 million are women (3, 4).

Especially, young women have become increasingly infected and the number of infected females between 15-19 years is more than twice the number of infected men

in the same age group. HIV prevalence is also high in antenatal clinic attendants. According to Sentinel Survey findings, HIV prevalence ranged from 3.2% in rural site (Ginir) to 23.4% in urban site (Bahir Dar (3).

A total of 107,575 HIV cases have been reported to the Ethiopian Ministry of Health Disease Prevention and Control Department since 1984. However, this figure shows only the tip of the iceberg and is not representative enough to show the situation in general, taking the poor health infrastructure and limited access to health care in to consideration (3).

The most important mode of HIV transmission in Ethiopia is heterosexual sex accounting for 86% of the reported cases. Mother to child transmission (MTCT) is also a major concern and accounts for 20% of the estimated cases. In a country with high fertility and a strong tradition of breastfeeding, MTCT will remain a major route of transmission (3). Illegal medical and harmful traditional practises involving cutting and piercing instruments are also common in the country. However, their contribution towards the disease burden is not studied and documented.

In Ethiopia, efforts made to control the pandemic have been focusing on the public health model of disease prevention. The strategies of this model focus on health education and provision of knowledge concerning prevention methods which is believed to result in reduction and if possible avoidance of the risk of acquiring HIV/AIDS by bringing about change in individual sexual behaviour (5).

The underlying assumption in this risk reduction model is that, once individuals know HIV's mode of transmission they perceive the risk associated with "unsafe sexual practices" and as a result decide not to indulge in risky sexual behaviour (6).



People have the right to know about factors of potential harm to their health and such knowledge is a necessary to change behaviours that will bring such harm. However, what can be achieved in changing sexual behaviours that expose to HIV infection by such knowledge is limited. Research has repeatedly shown that knowledge is insufficient to produce risk reducing behavioural change (7, 8). Especially researches done in Africa, even in countries hardest hit by the pandemic has shown that despite high level of awareness and knowledge as well as increased level of perceived vulnerability, there is little evidence of behavioural change (9, 10). For example a DHS report in Tanzania has shown that 98 % of men and 93 % of women were aware of AIDS in 1991-1992. Similar survey conducted in Kenya in 1998 has also shown that 99 % of men and women knew about AIDS (11). Further more the great majority of Africans in these countries knew of the dangers of sexual transmission (11).

According to the National Baseline Behavioural Surveillance Survey (BSS) conducted for the first time in Ethiopia on selected target groups<sup>1</sup> knowledge about HIV's sexual mode of transmission is found to be high in the total study population (98%). Nevertheless, HIV continues to infect and affect these groups at an alarming rate (3, 12).

The failure of the risk reduction strategy and persistence of high risk behaviour despite high level of knowledge in the vulnerable groups have been explained in this study in terms of low level of risk perception that resulted from lack of effective behavioural change interventions (12).

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<sup>1</sup> Target group refers to the group selected and received priority in HIV prevention and control efforts due to the high HIV prevalence, the target groups size and importance to the national economy in Ethiopia. This group includes school and out school youth, females sex workers, military personnel, farmers, pastoralists, long distance drivers and factory workers.

### **1.1.1 From individual behavioural risk to socio-cultural concerns**

Risk reduction strategies used in HIV prevention efforts more often are based on the theories of risk that are based on rational choice theories of action and thus operate with a strong concept of the autonomous individual (6,13). However, HIV/AIDS risk, especially with regard to the sexual mode of transmission is inescapably embedded in relation. It is constructed and considered by individuals together with partners. Such risk always involves relations and the individual is at risk in interaction with others. In other words, determinants of HIV related risks are relational, and hence, to an uncertain extent beyond the control of singular individuals.

More importantly, relations and interactions that might put individuals at risk are not always limited to their sexual relations. More often they are broad and encompass the non-sexual relations and cultural contexts in which individuals construct meanings, make their decisions, and deal with their socio cultural concerns. Also, since sex does not happen outside culture, understanding the circumstances that expose individuals to HIV infection requires investigation of the social relations, circumstances and cultural contexts in which their lives are situated and lived. With this understanding we may gain more accurate understanding of the influence of cultural, economic and political factors as well as social relations and institutional structures that constitute the contexts of individuals' behaviour in avoiding risk of HIV infection and coping with the consequences of HIV/AIDS.

### **1.1.2 Problematising safe sex**

There is a growing body of research on gender order and other social structures that contribute to HIV/AIDS vulnerability of women in one or another way (13-16). *Gender order* here refers to the social and cultural construction of gender identities as

well as institutionalised relations of power and privilege organised around gender difference (16). Studies on women and HIV/AIDS has shown how social, cultural, economic and political factors directly or indirectly relate to the gender institution and compromise women's ability to practice the prescribed "safe sex" (16-19). Even more important and logically prior to these, however, little research has started out by problematising "safe sex" and assuming that biomedically defined "safe sex" in the context of HIV/AIDS is situated amongst an unknown range of issues of relevance or significance with regard to safety, danger and risk in a culture.

Most "safe sex" discourses presuppose that safe sexual activity is the outcome of decision making that follows knowledge and risk perception. Even if it is assumed that "safe sex" is a risk free phenomenon from the biomedical point of view, it is not so if one sees risk from the broader social network angle, which encompasses the multiple socio-economic and cultural concerns that need to be taken into account. Hence, risk in individuals' sexual behaviour should be investigated not only in relation to HIV but also in relation to broader socio-economic concerns and cultural meanings that structure sexual practice within the collective flow of life (7, 13). This is so because, practising the prescribed "safe sex" or avoiding "risky sexual behaviour" may put people in another category of risk; risk of failing to deal with their socio-economic and cultural concerns including the struggle to keep one's social status by meeting social expectations and so forth.

Behaviours biomedically identified as risky could also be proscribed behaviours in other domains, such as the moral or relational, and relate to the social appropriateness of a certain kind of behaviours and relationship or relations of power within the relationships (18). In such situations, *general* cultural moral codes and/or those that are *specific* to gender and/or sexuality might contradict with the biomedically prescribed "safe sex" practice and create conflict of interests and dilemmas to the women and their partners that might have impact on practising the prescribed "safe sex". *Dilemma* here refers to difficult, perplexing or ambiguous choices between equally desirable or undesirable alternatives (19).

Little attention is given to such dilemmas that might arise and contribute to the vulnerability of women to HIV/AIDS when they attempt to prevent themselves and others from the infection by practising the biomedically prescribed "safe sex" and at the same time also try to meet the *general* moral and/or gender *specific* expectations in their cultural contexts.

Therefore, there is a need to do research in these areas. New knowledge generated in this field may contribute to the development of more appropriate HIV/AIDS prevention programmes. It is based upon this background that this study was proposed and conducted. The general objective of this study is to acquire new knowledge about phenomena that might contribute to increased vulnerability of Ethiopian women to HIV/AIDS, by exploring possible dilemmas that might arise while women try to protect themselves and others from HIV infection and also meet cultural expectations of what it is to be a moral woman. The specific objectives of the study will be described later.

### 1.1.3 Key concepts used in the study

Culture is a framework of knowledge, beliefs, expressive symbols and values, in terms of which individuals define their world, express their feelings and make their judgements (20). It comprises systems of shared ideas, systems of concepts and rules and meanings that underlie human life (21). It also provides a framework for constructing moral scripts and meaning orders that delineate among other things the right from the wrong, and the moral from the immoral members of society. The term *moral* here refers to concern with the rules of right conduct (19). Rules of right conduct are culturally determined yet they are not always applicable in all contexts and are not permanent. By *Scripts* I mean culturally proscribed codes for interactions between people both verbally articulated and those that have not been verbally articulated but implicitly understood guides for behaviour between people responding to each other's cues and actions (22). They are negotiated and shared among a group of people in a culture. Hence, they also operate at the individual level shaping an individual's own attitude and expectation.

The delineation criteria provided by the cultural framework takes the form of dominant meanings, values and standards that dictate which practices are "good" or "bad"; "natural" or "unnatural"; "decent" or "indecent" thereby establishing the frontier between the normal, the normative, and the abnormal. The scope of the value framework may vary, and even if only to a very limited degree; it will provide a scope for interpretation and negotiation.

Neither the cultural framework itself nor the delineation criteria provided by moral scripts and meaning orders are, however, constructed outside power relationship. Therefore, both meaning orders and moral scripts are mechanisms that reflect the interest of the dominant groups in society, to produce, reproduce and legitimatise the existing social order (23). Gender order and gender based differential moral values and scripts are among the regulatory mechanisms of social order to perpetuate the existing gender power imbalance. *Gender* here refers to the web of cultural symbols, norms, institutional structures and internalised self-image, which through the process of social construction defines what is meant by masculine and feminine (24).

Societal expectations of a woman's behaviour in a culture could be in relation to *general* scripts of moral codes governing interpersonal relationships, or could be gender *specific* scripts for specific status, e.g. "mother", "sex worker" etc. Such gender *specific* scripts refer to patterns for interaction between women and men that are socio- culturally defined and influence the way gender, sexuality and relationships are constructed (22). Hence, they also dictate which kinds of relationships are approved and

which are sanctioned and thus may be a threat to one's reputation in a culture. Consequently, women's inability to practice the prescribed "safe sex" needs to be investigated from broader dimensions which include both *general* scripts of moral codes, which of course are gendered in practice, and those that are *specific* to gender and/or sexuality. *Sexuality* here refers to the social construction of a biological drive which incorporates collective and individual understandings about the nature of the body, about what is considered erotic or offensive, pleasurable and harmful, natural and unnatural. It also refers to with whom and what is appropriate or inappropriate for men or women, according to their age and other characteristics, to do or to say about sexuality (24). Individual's sexuality is defined by whom one has sex with, in what ways, why, under what circumstances and with what outcome and by one's sexual orientation acts and identity (14, 15, 24).

### **1.1.4 Structure of the thesis**

The remaining part of this chapter discusses part of the literature review and the study objectives. Following this, the theoretical aspect of the research methodology used; the rationale for method choice and the challenges faced and the lessons learnt from using the method in practice will be discussed in the second chapter.

In the third chapter, Ethiopia's profile; the objectives and the organisation of the National HIV prevention efforts and the situation of women in Ethiopia will be discussed.

The ethnographic description in which I have attempted to show the context in which the day to day life of majority of Ethiopian women is situated and their HIV/AIDS related dilemmas are created is given in the fourth chapter.

In the fifth chapter, I have attempted to discuss sexual norms and their moral implications in Ethiopia, which are necessary to understand the possible reasons for the association made between moral disorder and HIV/AIDS infection.

The women's experience of HIV/AIDS stigma, the association made between moral disorder and their serostatus and major contributing factors for the association will be discussed in the sixth chapter.

The seventh chapter discusses the challenges and dilemmas the women living with HIV/AIDS face due to stigma. It also discusses the mechanisms they use in the

struggle not only to maintain their social status and respect for themselves and their loved ones but also to cope with consequences of HIV/AIDS stigma and stay alive.

The thesis ends by giving summary of the findings and pointing further research needs in the eighth chapter.

## **1.2 Literature Review**

This literature review is a pre-fieldwork literature review. It has been reviewed during the project proposal development process to assist in identification of knowledge gap. The need for further literature review consultation emerged both before and during the fieldwork and I have been consulting further literature. During the fieldwork, after the proposal has been developed, it became necessary to expand the scope of the investigation and include *stigma* since it turned out to be intrinsic to the themes under inquiry. Hence, further literature consulted in relation to stigma and its consequences is not included in *this* pre-fieldwork literature review. Further literature consulted in relation to stigma will be discussed in chapters 5-7.

### **1.2.1 Gender role and HIV/AIDS**

The powerful influence that gender roles and gender power relations exert in fuelling the HIV/AIDS epidemic has been well studied and documented (13, 14, 16). Multiple studies have shown how gender related factors shape the extent to which men and women, boys and girls, are vulnerable to HIV infection and the ways in which their ability to protect themselves against AIDS and to cope with its impacts are affected. Among these are different attributes and roles societies assign to male and female (14, 16). For example social constructions of masculinity define male as heterosexual, virile, knowledgeable, promiscuous, aggressive and in control of his environment

including women around him (25). Hence, *first*, men fail to admit their lack of knowledge regarding HIV prevention practices. For example studies done in Brazil have shown that young men did not ask questions despite their lack of knowledge about STD/HIV preventive practices for fear that others will find out that they are not knowledgeable (26). *Second*, multiple sexual partnerships and promiscuity of men are implicitly or explicitly condoned in many cultures. Hence men involve in multiple relationship to fulfil this expectation although it will put them at increased HIV risk. Studies done in different parts of the world reflected the persistence of such social construction of male sexuality. For example, study done in Nigeria to examine perceptions and practices and norms underlying sexuality and gender relations that constrain the prevention and control of STI's and HIV/AIDS has shown that multiple sexual relationship of men condoned by the culture, is among the factors that expose men to increased HIV risk (27). Similar finding was also reported by a study done in Uganda (28). A study done in Nicaragua has also shown that even though it puts them at increased risk of contracting HIV, men involvement in multiple sexual relationships is encouraged by the society and they will be ridiculed and their masculinity will be questioned if they do not comply with this expectation (29). The *third* reason that increases men's vulnerability to HIV is the expected role of men to be in control of their environment including their female partner's sexuality. Men in such cultures are not willing to comply with women's suggestion on protective practices such as condom use because they believe that it is losing control. For example in a study in Nigeria men in the study explained that women's condom suggestion or refusal to have sex is unacceptable since controlling sexual relationship is considered a man's territory (27).

Social construction of femininity on the other hand defines female as passive, placing the need and desires of her male partner before her own (30). This social construction and traditional gender role socialisation make women vulnerable to HIV infection because it prevent them from suggesting and utilising protective practices like condom use or refusing sex which could expose them to HIV risk. This is because it is considered to be against the expected passive gender role of women in sexual matters (27, 16). The influence of such social feminine constructions in increasing the vulnerability of women to HIV infection has been studied and documented. For example according to a study done in, Ethiopia, social feminine constructions that expect women to be passive and give privileges for men to be sexually active and in control was among the norms identified for the increased vulnerability of young women (31).

Studies done on the women gender in relation to HIV vulnerability have shown that in addition to the social construction of femininity, women are more vulnerable than men because of multiple reasons. First, women are physiologically more vulnerable than men. Male to female HIV transmission is significantly higher than female to male transmission due to three reasons. *First*, there is greater amount of HIV in semen as compared to vaginal or cervical secretion (32). *Second*, since vagina has greater surface area exposed to the virus compared to male genitalia, the efficacy of the virus transmission is increased. *Third*, since vagina serves as a receptacle, it is exposed to HIV for longer period compared to male genitalia, which has briefer contact (32).

In addition to the physiological vulnerability, girls and women, in most society face heavier risk of HIV infection due to gender based inequalities. Different studies have shown the role of gender inequality in compromising women's ability to practice safe sex (13, 14, 27, 33) that overlap with other socio-cultural factors (17, 29, 31, 34). One



of these factors is women's limited access to education and economic opportunities. Since low level of education or lack of education means few marketable skills, many uneducated women have no access to employment opportunities. Hence, they have no power in making decisions including sexual relationships and use of protection. Also, many of the poorest are women and engage in unprotected sex as a survival strategy. Research in many parts of the world has shown that women involve in sexual relationships that might expose them to HIV to fulfil their basic economic needs. For example, studies done in Tanzania, Nigeria Brazil, Ethiopia and Ghana have shown the association between women's limited access to economic opportunities and failure to practice "safe sex" (13, 26, 27, 31, 35).

War and systematically targeted sexual abuse are also among the political factors that increase the HIV vulnerability of women. Studies in east and central Africa have shown that, patterns of female HIV infection have been correlated with the movement of the military (36). For example in Rwanda, 70% of some 25-50,000 women raped in 1994 genocide directed against the ethnic Tutsis are estimated to be HIV positive (37).

### **1.2.2 Women culture and HIV/AIDS**

Research on the area of culture, women and HIV/AIDS has also explored and described cultural norms and ideal feminine attributes that could prevent "safe sex" practice and thereby make women vulnerable to HIV infection in various parts of the world. Some of the literature on this area will be discussed below.

#### ***Some ideal feminine attributes that limit women's access to information***

Research has shown that ideal feminine attributes in many cultures typically emphasise sexual innocence and many cultures consider female ignorance of sexual

matters as a sign of purity (34, 38, 39). Hence, unmarried girls and women are poorly informed about basic reproductive and sexual physiology (40, 41). They do not also dare to ask questions or seek information about sexual and reproductive matters. As a result of this, firstly, it is difficult to inform them about HIV risk reduction and ways to protect themselves and others from the infection because it is contradictory to their cultural norms of being ignorant on sexual matters. Here this specific knowledge in this context is dangerous to the girls in the sense that it has the capacity to pollute them.

Secondly, this lack of basic information about reproductive physiology and sexual matters may prevent them from recognising the symptoms and seeking treatment for sexually transmitted diseases. This further increases their vulnerability to HIV infection (41, 42). For example a study done in India has shown that women take itching and vaginal discharge as inevitable part of their womanhood (43).

Many societies place high value on virginity of young, unmarried women and safeguarding their virginity is part of their gender script. In such societies, young women who seek information and care regarding sexual health matters or know how to use condom may be viewed as sexually active and promiscuous despite the true extent of their sexual activity (44, 39). For example, studies in Nicaragua has shown that unmarried women fear that even seeking information about reproductive health matters will imply that they are sexually active and jeopardise their reputation (29). It jeopardises their reputation because the implied premarital sexual activity is contradictory to the norm of premarital sexual abstinence of girls in their culture.

### ***Some factors that limit women's ability to practice safe sex***

Gender related cultural factors that increase the vulnerability of women to HIV/AIDS are not only factors that limit their access to information. Some are attributes that prevent them from practising “safe sex” despite knowledge of preventive practices. In societies where virginity is given high value and knowledge of sexual matters is considered as a sign of easy virtue, despite knowledge of “safe sex”, women were not able to ask for and utilise protective practices. This is because they are trapped in preserving knowledge for fear that they may be considered as mocked if significant others could find out that they are sexually active and question their virginity (44-45). Ideal feminine attributes also contribute to the vulnerability of women to HIV/AIDS in many ways. Some among these are social expectations that woman should please men; they should remain virgin until married and must give children.

### ***Pleasing men***

In some cultures pleasing men is seen as the ideal feminine characteristic of a good woman. Studies done have shown that women living in such cultures some times engage in behaviour that will increase their likely hood of being infected with HIV because they believe that it is pleasurable to men (46, 47). For example a study done in Zimbabwe have shown that women prepare, modify and tighten their vaginal passage that they think is more satisfying and pleasurable to their sexual partner or husband by putting herbs into their vagina. The herbs cause inflammation, laceration and abrasion that could significantly increase the likelihood of HIV transmission (46). A study in South Africa reported similar findings. According to this study the women in South Africa used scouring powders in addition to herbs and roots (47).

Another practice that is found to increases women’s risk of acquiring HIV and yet practised to please men is anal sex. For example studies done in Brazil have shown that women engage in anal sex for their partner’s pleasure and to satisfy their sexual partners demand even though it puts them at increased risk of acquiring HIV (48). Study done in Zaire has also reported the presence of the same practice (49).

## ***Virginity***

Remaining virgin and abstaining from sexual intercourse until married is among the suggested prevention measures against HIV/AIDS. However in cultures where high premium is given to virginity and where virginity for unmarried girls is norm, girls have been vulnerable to HIV infection *because* of their virginity.

First, in the age of HIV, virginity signifies cleanliness and thus freedom from disease. Since younger girls are believed to be less likely to be infected, older men with a lot of sexual exposure and unknown HIV status seek for younger girls and have sex with them to avoid their fear of being exposed to HIV infection, (50). This age mixing put the young girls at increased risk of HIV because of two main reasons: *firstly*, their reproductive tract is not fully developed and have few layers of epithelial cells which offer a less effective barrier against viral infection. *Secondly* these men are more likely to be carriers due to the possible multiple, concurrent or serial sexual partners that they have prior to meeting the young girls. Hence, the young girls could be exposed to increased risk of HIV infection (51). The notion that female virginity symbolises innocence and passivity that some men find erotic, have been also exposing virgin girls to sexual coercion and rape that could expose them to HIV infection (48).

Another reason that exposes virgin girls to HIV infection according to research findings is the belief that sex with virgin can cleanse a man from infection (49, 50, 52). It is being reported that HIV/AIDS infected men rape young adolescent women even female children because they believe that the 'pure' virgin body has the capacity to 'clean' HIV infected man and thus cure him from the infection. For example in South Africa, men who are already infected with the virus had raped and exposed female children to HIV infection (52). In addition to the already known HIV status of the person attacking them, rape increases the risk of acquiring HIV. This is because with forced intercourse abrasions and cuts which increase the biological risk of HIV transmission are more likely to occur (49).

Research has also shown that some women practice alternative sexual practices to preserve their virginity. For example studies done in Brazil have shown that women practice anal intercourse in order to preserve their virginity although this behaviour may put them at increased risk of acquiring HIV (53). A study done in Zaire has also shown that 19 of college students reported engaging in anal intercourse. Preserving virginity was among the reasons given for the practice (51).

## ***Motherhood and fertility***

In cultures where motherhood has been taken as an ideal feminine role and women's value is attached to their fertility, it becomes difficult for women to choose between fertility and using barrier methods for HIV prevention. This is aggravated in cultures, where children are viewed as a source of labour for the family and security for their parent's old age (54, 55). In such

cultures continuing fertility is associated with virtue and reproductive failure with punishment and evil (56). Hence, a woman's infertility is taken as an adequate reason for divorce. For example in Ethiopia bareness is among the most common reasons cited for dissolving marriage (57). A study done in Tanzania has also reported similar finding (58). Women in such cultures may engage in multiple sexual partnerships in the hope of getting a child or children and saving their marriage. For example a study done in Mozambique has shown that engaging in extra marital sexual relationship in the hope of getting a child is among the strategies used by married women with fertility problems (59). Similar finding was reported in Tanzania (58). This practise could expose them to HIV infection.

When the women's effort to conceive fail and divorce follows, they are left without any economic security and their only option will be to continuously engage in multiple sexual relationships for economic reasons. This further increases their vulnerability to HIV/AIDS (41, 60).

### **1.2.3 Summary of the literature review on gender, women and HIV/AIDS**

In the literature reviewed, how gender role socialisation and gender based inequalities, overlap with other social, cultural, economic and political inequalities and compromise women's ability to practice "safe sex" and thereby increase their vulnerability to HIV/AIDS has been studied and documented (34-60). From the literature reviewed on culture, women and HIV/AIDS findings of the studies could be put into two categories. The first, are factors that limit women's access to information about reproductive and sexual matters including "safe sex" practice and thereby expose them to HIV infection. The second are factors that mediate their ability to practice "safe sex" despite knowledge of practices that have high risk for HIV infection.

### **1.2.4 Knowledge gaps identified in the reviewed literature**

In the literature reviewed in gender, culture, women and HIV/AIDS only two survey studies conducted in Ethiopia focused on socio-cultural contexts and psychosocial determinates of HIV infection transmission. These studies focused on specified target groups (school youth and out school youth) to identify socio-cultural contexts and

psychosocial determinates that might mediate young people's ability to practice "safe sex". (31, 33) The Findings of these studies have shown the role of social feminine construction in increasing the vulnerability of women to HIV/AIDS by compromising their ability to negotiate for "safe sex". The studies also shown that women are at increased risk of HIV infection and described how gender power differences in sexual relations significantly influence sexual behaviour.

However firstly, none of the investigations done in Ethiopia focused on HIV infected women and investigated the issue from the lived experiences of the women.

Secondly, none of the studies started out by assuming that "safe sex" in the context of HIV/AIDS is situated amongst an unknown range of issues of relevance or significance with regard to safety, danger and risk in a culture. Consequently, they did not attempt to investigate general cultural moral codes and/or those that are *specific* to gender and/or sexuality that might contradict with the biomedically prescribed "safe sex" practice and creates conflict of interests and dilemmas to women that might contribute to their increased vulnerability.

Thirdly, although relations and interactions that might put women to HIV/AIDS risk are not always limited to their sexuality and encompass the none sexual relations and contexts of their life such as *general* cultural scripts governing interpersonal relationships, the possible relationship between the "taken for granted" *general* cultural scripts structuring and governing interpersonal encounters that might be *deducted* into sexual relationships and mediate the women's ability to practice "safe sex" have not been explored in the Ethiopian context to the best of my knowledge.

Last but not least, although there are cultural moral values and expectations attached to the female gender *shared* among different cultures, the importance and priority given to these values and expectations vary from culture to culture. Consequently, one would not expect findings from study of one culture would also apply to another culture in all areas. To the best of my knowledge this is the first study that focuses on cultural moral values and gender scripts of women in Ethiopia. Consequently there might be values and expectations specific to Ethiopian women that might contribute to their increased vulnerability for HIV/AIDS that haven not yet been explored.

Therefore, there is a need to do research to fill the identified knowledge gaps. The finding of this research might help to get a better understanding of these issues for those working to reduce the rate of HIV infection in general and those working with women and HIV/AIDS in particular.



## 1.3 Objectives of the study

Based on experience and the knowledge gap identified the following objectives were formulated.

### General Objectives

To acquire new knowledge about phenomena that might contribute to increased vulnerability of Ethiopian women for HIV/ AIDS, by exploring moral and/or gender scripts that might create dilemmas while women try to protect themselves and others from HIV infection and also meet cultural expectations of what it is to be a moral woman.

### Specific Objectives

All the specific objectives except for objective number 6 were formulated during the pre-fieldwork period. The sixth objective was added later after stigma turned out to be intrinsic to the themes of the inquiry.

- ◆ To explore the understanding of safety, and danger with regard to sexual practice and relationships.
- ◆ To explore understandings of HIV/AIDS candidacy, susceptibility and vulnerability.
- ◆ To explore the links people make or do not make between the notions of HIV/AIDS related risk and their own experience and narration with respect to gender.
- ◆ To explore possible alternative protective practices used for HIV prevention.
- ◆ To explore the ways in which biomedically prescribed HIV prevention practices are understood with regard to threat to a moral person and/or gendered expectations of a woman.
- ◆ To explore the women's HIV/AIDS related stigma experiences and dilemmas



- ◆ To identify unacknowledged potential for prevention and to improve prevention efforts already on operation.

## Chapter II

### Research methodology, sample and sites

#### 2.1 Research methodology and approach

No one research method is intrinsically superior to other methods since reality exists in the empirical world not in the methods.

The value of the methods exists only in their suitability in enabling the research task to be done and the choice of the best method always comes from the research purpose (61). Qualitative method was chosen for this study with this understanding. This study did not aim to establish correlation but to critically investigate unknown phenomena that might increase women's vulnerability. Hence, quantitative method is not applicable.

This study is about issues that created dilemmas in the women's minds that might have compromised their ability to protect themselves from HIV/AIDS. Such issue can best be learnt from the participants in their cultural setting and process, from the way they experience them, the meanings they put on and attribute to them and their situational interpretation. Hence, qualitative method is found to be the most appropriate method of choice that provides such opportunity (61).

As described earlier, the aim of the study is to critically investigate unknown phenomena that might increase women's vulnerability to HIV/AIDS. As such aim may expect to involve themes that can neither be verbally or otherwise articulated (e.g. through images) nor fully recognised by the subjects of the study or the researcher, exploratory qualitative method was found to be the most appropriate (62).

The approach that was used for this research was ethnographic fieldwork. Such approach was chosen for this study because its holistic contextual and reflexive nature enables the researcher to explore phenomena within a cultural context from the *emic* perspective and investigate and describe the social and cultural scenes of moral personhood. In this study it is used in the hope of investigating, understanding and describing moral and gender *specific* scripts of the women that created dilemma and mediated their ability to practice "safe sex" from their perspectives and lived realities.

The phenomenon under study is complex, multifaceted, deeply rooted and embedded in the socio-cultural contexts. Hence, exploring, understanding and describing such phenomena is impossible through a single data gathering technique. Ethnographic approach provides opportunity to get wide-range of data combining different data gathering techniques such as covertly or overtly participating in daily lives of people for extended period of time, watching what happens, listening to what is said, asking questions, analysing discourses (63). Hence this approach is found to be the most appropriate approach for this study.

Data gathering techniques employed in the fieldwork included: participatory observation, dialogic interview and discourse analysis. Combination of these methods was used in an attempt to get data from a wide-range of sources in the hope that combining such methods would make it possible to approach the phenomena under investigation from different but complementary angles and hence counterbalance the weaknesses and biases of the individual methods (triangulation) (62,63).

Although the methods are separated for the purpose of discussing sources of ethnographic material, in the fieldwork these methods were mutually dependent. This is not however a weakness, but rather a potential strength because the various elements of the fieldwork were allowed to inform, and complement each other.

### **2.1.1 Summary of data gathering techniques employed**

Three data gathering techniques were employed for this study. These techniques will be discussed further below. The *first* was through four months of participatory observation which included participating and observing day to day activities of Tesfa Goh organisation and its community, participating in counselling sessions, and the exhibition conducted in Addis Ababa *Meskel* square. The *second* was repeated dialogic interview. Altogether, a total of 67 interviews were conducted with 15 women.

Discourse analysis constituted the *third* data gathering technique, which included public discourses and dialogues from the organisation's community on the topic of the study

## **2.2 Research setting**

The major study settings for this study are Addis Ababa and Nazareth Tesfa Goh Ethiopia offices. In addition to serving as a research setting, these offices were also used to create other research options.

Tesfa Goh (Down of hope) Ethiopia is the biggest non-governmental HIV/AIDS patients organisation established by 11 Ethiopians living with HIV /AIDS in 1998. The main objective of the organisation is participating in prevention and control of the spread of HIV/AIDS and helping to protect the human rights of people living with HIV/AIDS. It has 7 branch offices in different regions of the country and the activities of the organisation include health education and advocacy, provision of training to health educators and home care providers, provision of care and support, medical supplies for opportunistic infections, counselling and orphan care. It includes both sexes and has about 3,000 members nationally (65).

There are two types of membership based on HIV serostatus: full membership and associate membership. A person is entitled to be full member if she/he is HIV positive or lost his/her parents due to AIDS. Others are granted associate membership (62).

This organisation was chosen as an entry point and study setting because of three main reasons. First, it provides a chance to meet and observe people with different gender, socio-economic, educational and HIV serostatus. Secondly, it gives opportunity to recruit participants with maximum variation which allows for investigation of a broad range of phenomena related to the research topic that the maximum is hoped to be learnt within the given short period of time. After stigma became important part of the study in the research process, it also provided

opportunity to see the process of becoming an HIV positive person as a public process, which holds a potential for understanding better what is involved in the process of stigmatisation and establishing identity of a moral HIV positive woman.

Among the seven branch offices of Tesfa Goh, two namely the Addis Ababa branch office and the Nazareth branch offices were used for this study.

### ***The Addis Ababa branch office***

Tesfa Goh Addis Ababa branch office is found in Woreda 8 Kebele 15 in Addis Ababa, the capital city of Ethiopia. It is an old ground plus one wooden house with a 400 square metre compound surrounded by a tall fence made of stone. It has 5 small rooms on the first floor which are used for office work and the basement is used for giving health teaching and showing educational video films. It has additional 5 rooms in the compound used for office work as well. There is also a small tea-room in the compound run by one of the organisation's members.

The inner side of the office wall is covered with posters and slogans that carry different messages about HIV/AIDS prevention and care; advantages of voluntary testing and some pictures of people who established the organisation.

There are about 15 people currently working as permanent employees of the organisation. Except for one person, who is working as an accountant employed by a local NGO to support Tesfa Goh's activities, all employees are HIV positive. This number, however, does not include those that are not employed but are providing home based care and teaching the public about HIV/AIDS.

The place is always busy and there is too much to be done. Home based care providers come to the office after assessing the needs of the patients they are providing care for. They come also to the organisation to collect drugs for the treatment of opportunistic infections that the bed-ridden patients suffer from. A small

old car owned by the organisation serves as an ambulance to take critically sick or weak patients to health institutions based on the report of the home care providers. People working there do not go out on time for lunch or coffee break and frequently work outside office hours: counselling, writing letters to members to get a chance for free treatment, providing drugs for people who suffer from opportunistic infection and cannot afford to buy drugs etc. They also plan and prepare schedules with different organisations and assign members to go out and teach the public in order to “give a face” to the syndrome.

People also come to the office with the hope of getting economic support but the office has very limited resources compared to the demand. According to the office, in addition to the resource limitation to provide such support for the needy and to run the activities as planned, the usual delay in the allocated budget transfer from donating organisations is among the reasons that create a problem in doing the activities as planned.

On average 15-20 people who had been pushed away by their neighbours, families, and/or have no income to support themselves and their family flow to the office every day hoping to get help. More women came to the organisation than men. Counselling service is given but the very busy schedule and shortage of human power makes fulfilling the very high demand for continuous counselling difficult. So priority is given to newcomers. Even though the formal counselling service could not fulfil the continuous demand, once someone enters in the compound at least there is no time to feel lonely. Those who usually come to the office and have been members for some time identify newcomers easily. They introduce themselves to the newcomers and try to make them comfortable.

In the small tea-room in the compound, there are no chairs or tables. Traditional coffee-pot is used to make coffee and an old kettle for making tea. The tea-room is a place for discussion and sharing problems. Although people coming to the office have different social and economic background, one feels the friendship spirit. Some come to the tea-room after they finished teaching about HIV/AIDS wherever they have been assigned by the organisation. They share their experience, the problems they faced while they were teaching and how they managed to solve them. Some come after they finish their home based care and inform the group who is seriously sick and who needs to be visited. Others come to see friends and chat about their health problems and the problems they have faced due to their serostatus and receive advice and encouragement.

### ***The Nazareth branch office***

The Nazareth Tesfa Goh branch office is the second research site used for this study in addition to the Addis Ababa branch. The Nazareth branch office is found in Nazareth, the capital city of the Oromia Regional State, which has 189,000 inhabitants and located 100 kilometres away from Addis Ababa. The Nazareth branch office does not have a big office in contrast to the Addis branch and has only two rooms, however, they basically offer the same service.

There are two big slogans hanging on the inner wall of the office, which say:

**“We are at risk but we will rescue others!”**

**“I go to my grave with the virus I have, to let it be buried with me. That is the control method as a share of duty given to me.”**

The office has four permanent employees. This number does not include those providing home based care and those giving health education to the public.

In addition to the small size of the office the absence of a place for a friendly chat like the one provided by the Addis Ababa branch office tea-room, made the interaction of the members limited and their chance for discussion of their problems and sharing their experiences minimal. Because of this I was not able to observe the interaction and participate in the discussions as I have done in the Addis Ababa branch office small tearoom. However, I was able to interview members and participate in a counselling session.

## **2.3 Data gathering techniques**

### **2.3.1 Participatory Observation**

The main part of the participatory observation took place in Tesfa Goh Ethiopia Addis Ababa Branch office, in the day to day of activities of the Tesfa Goh organisation and its community. It included participation in the counselling sessions conducted from June to November 2003 as well participating in the exhibition conducted under the slogan “Zimta wiyiseber” (let’s break the silence).

Participatory observation is a technique of subjective data collection, which involves a researcher spending time in an environment observing behaviours, actions and interactions, so that she/he can understand the meaning constructed in the environment and make sense of every day life (62, 64). This approach was used to get data from on going activities such as day to day interaction of Tesfa Goh organisation and its community and counselling sessions that were conducted by the two branch offices of Tesfa Goh during the study period.

Participatory observation has been found to be useful for this study because it enables to observe people’s interaction. The main purpose of choosing this method for the study over other methods was its powerful advantage in providing opportunity to contextualize statements and actions in familiarity with individuals over time.

In this study, it was used to understand both the explicitly formulated and implicitly embodied expectations of what it is to be a moral person from the interaction of the organisation’s community and the advocacy of the organisation. It was also used in order to identify tacit and “taken for granted” notions/dimensions of what it is to be a moral woman. Participating and observing in the counselling sessions and the day to day life of the organisation and every day contact with the study participants provided opportunity to contextualize their statements and actions in a familiarity with individuals participating in the study over time.

For the participatory observation all participants of the counselling session and day to day activities of the organisation were included irrespective of gender and serostatus difference.

#### ***Counselling sessions***



Access to participate in the counselling sessions was gained through Addis and Nazareth Tesfa Goh offices. Before I was allowed to go into the counselling room and observe and participate, all the 7 people counselled were asked for their consent. I was allowed to come in after the counsellors got the consent from them. During the study period 7 formal counselling sessions (6 in the Addis Ababa branch office and 1 session in Nazareth) were attended. Among the 7 people counselled 3 were men and 4 were women.

Counselling is among the main activities of the organisation and the organisation community. The formal counselling sessions I have attended were conducted by two men (one for the Addis and one for Nazareth branch offices) who are trained in counselling and are full member of the organisation. New members coming to the office will at least have one formal counselling session. However a lot of informal counselling sessions were conducted by the organisation's community. I have attended such sessions at least 3 times per week during the study period.

### ***The exhibition***

Another important site for participatory observation was the one-week exhibition that was open to the public from September 6-11 in Addis Ababa *Meskel* Square under the slogan “*Zimta w yiseber*” (let’s break the silence).

Participating in the exhibition gave me a chance to listen to discussions, discourses and dialogues on the topic of the study. Thirty organisations working in the area of HIV/AIDS throughout different regions of the country, including Tesfa Goh, participated in the exhibition. Each organisation was given a tent to show its activities. Among the activities included in the exhibition were sharing experiences in teaching about HIV/AIDS and stigma reduction through different community based traditional approaches, information provision regarding HIV testing and introduction of institutions providing service. The exhibition also provided forum for discussion of different issues among people who disclosed their serostatus and the participants of the exhibition. In addition to the open panel discussion individuals were also given a chance to get information and discuss their fears and doubts about HIV/AIDS and their unknown serostatus individually with assigned individuals in each tent. Entertaining activities such as music and short drama shows were also part of the exhibition. The exhibition was attended by a lot of people from different age groups and generations.

Lastly, data from the participatory observation was also used to feed into and facilitate the interviews (see below).

### **2.3.2 Qualitative Dialogic Interview**

#### ***Sample and frequency of interviews***

The formal repeated dialogic interview was conducted from August to November 2003. Of the women who participated in the dialogic interview, four were recruited from Nazareth and 11 were from Addis Ababa. Among the total 15 women that participated in the dialogic interview the minimum age was 19 years and the maximum was 50. Three were still married, two were separated, five were widows and five were never married. On their occupational status, 5 were students, 4 were employed and 2 have small businesses of their own to run whereas 4 were unemployed. The participants' educational level varied from ability to read and write to completion of tertiary education.

For the interview, the study population was women aged 18 years and above and who are full members of Tesfa Goh Ethiopia. As generalisation in statistical sense was not the objective of the research, none-probabilistic sampling method was chosen and purposeful sampling, that is, selecting a sample from a limited universe (Tesfa Goh community) with maximum variation, so as to allow for inquiry into a good range of phenomena was used. Hence, women with different age, educational back ground, economic status and religious affiliations were recruited for the dialogic interview.

The core group for the study was 15 women recruited for the interview using Tesfa Goh Ethiopia Addis Ababa Head office and Nazareth branch office. During recruitment attempt was made to recruit participants with different age group, educational back ground, economic status and religious affiliations. I participated in the recruitment process working with the organisations branch offices.

Participants were interviewed more than once (see below). A total of 67 interviews were conducted. Each first interview lasted 2-3 hours on average. For subsequent interviews the time varied according to the issue that needed further exploration.

10 women were interviewed 6 times

2 women were interviewed 2 times

2 women were interviewed 3 times and

1 woman was interviewed only once.

### ***The Qualitative Interview***

Qualitative interviewing is a way of attempting to understand the world from the subject's point of view, to unfold the meaning of people's experiences and to uncover their lived world (63). Such an approach allows for understanding the women's actions that exposed them to HIV infection from the participants' point of view. Another reason for choosing dialogic interview for this research was the powerful nature of interview in creating forum for the women, as partners in knowledge generation, to make explicit things that their hitherto have been implicit, to articulate their tacit perceptions, feelings and understandings. Hence, this approach was originally chosen in order to facilitate self-reflection and possible insight. Through their own story telling, some participants might come to reflect on previously natural seeming matters in their own culture (67). Such process of self-reflection is part of the fabric of this thesis. The identity of the researcher will be discussed later.

Repeated interview was chosen in order to have a chance for repeated follow up, crosschecking and exploring further phenomena that emerged in interviews with other women. Conducting several interviews with each of the women allowed for such cross checking, follow up and further exploration of relevant issues that emerged during the interview process with other women. In addition to this it gave the women a chance to discuss issues that they did not open up in the earlier sessions. The repeated interview also provided opportunities for mentioning and discussing issues that they forgot to mention in the previous session and issues that they considered unimportant until they understood the relationship through their self-exploration and reflection.

I have prepared the interview guide for the initial interview in English and translated it to Amharic and back to English. It consisted of semi-structured open-ended questions in the sense that the interview is conducted according to a list of items/ issues to be covered. The sequencing of the issues depended on the flow of each interview question. It was piloted to check on the meaning of the questions to the interviewee and the duration of the interview on two women. Restructuring was not found to be necessary. Subsequent interviews were planned individually and the interview guide for the subsequent interviews was prepared in Amharic. There was no specific place for conducting the interview and the choice of the place was made by the participants of the study individually. None of the interviews were conducted in the branch offices. While conducting the interview notes were taken carefully based on the women's consent.

### ***Reflection of participants***

I would like to mention that as the dialogic interviews facilitated self-reflection and indeed became fora for self reflection, such reflection became part of the empirical data. In the beginning of the dialogic interview, especially on issues related to reasons for not using condom despite knowledge and risk perception, the responses of some of the participants were at a category level, that is, without reflecting on the individual configuration of their own experience which is particular perhaps even unique for their situation. They identified themselves with a category of people who shared the experience of failing to practice ABC's of HIV prevention i.e. abstain, be faithful and use condom.

For example, Yeshiwork responding to this question "how did you get infected"? Said:

*...I became infected in the way others did. Sex with out condom...*

Alemitu responding to this same question said:

*...I became infected because I had not been faithful to my fiancé and I did not use condom with my other boyfriend...*

This might show that some might not have asked the question what made them vulnerable at that particular situation in the first place at an individual level. During the repeated interview processes while narrating their lived realities, some were able to explore and understand at least some of the possible reasons for failing to practice "safe sex".

Ayelech reflecting on this she said:

*...I used to think that I failed to do what I was supposed to do and became infected because I have been careless; but now I know that at least I may have had some reason for doing it. May be I should stop blaming myself..*

### 2.3.3 Discourse Analysis

What is in the media during the study period about issues related to sex/gender/moral and HIV/AIDS was closely followed. In addition to this, traditional stories, folk tales and other aestheticizings were looked into. Material for the analysis was also obtained through the participatory observation, dialogic interviews, everyday conversations and small talks between members and the researcher.

Discourses are social and cultural dialogues. Meanings are socially and historically produced as well as reproduced and transformed within and in interaction with discourses: general and specific; dominant and subversive. I use discourse here in a broad sense, including verbal dialogues and statements, as well as the non-verbalised dimensions of discourses.

Discourses are socially conditioned and socially constitutive, reflecting and structuring the cultural and religious understandings and expressions of a society. Discourse analysis was included in this study in order to facilitate closer examinations of implicit and explicit social and cultural codes for behaviour, thoughts, perceptions and understandings. It was employed at different levels; both discourses in the *general* cultural and religious contexts (usually called public discourse) and the *specific* discourses at the level of Tesfa Goh's community.

The *first* level was exploration of public discourses in the general cultural and religious contexts in relation to the research topic. Coverage in the media is implicitly or explicitly often about personhood and deals with interpersonal relations. Such coverage was followed and analysed during the whole study period. Since I am an Ethiopian, (further identity will be dealt with separately below) this approach was used in the hope of eliciting a better understanding of the unconscious narratives we share as Ethiopians, ones we think through but rarely think about.

As stigma came to be focal in the research process, investigation of discourses especially the dominant ones became vital. Examples of dominant discourses are religious discourses about cause and purpose of the HIV/AIDS, public health discourses of HIV/AIDS likely candidates etc. Part of the work of dominant discourses is to exclude or suppress the possibility of other

discourses being listened to or subordinate other discourses. To pay attention to discourses was found useful in an effort to understand and explore stigma as a relational construct, both at intrapersonal and at interpersonal level.

The *second* level was analysis of the specific discourses. Material was gathered through participation in and observation of the interaction of Tesfa Gogh's community, small talks, informal and formal counselling including advocacy of the organisation on behalf of the members. In accordance with the research focus, particular emphasis was given to analysis of dialogues in the area of expectations and understandings of a moral person/woman.

## **2.4 Recording by hand versus by tape**

I used tape record for the first 3 interviews. Before the formal interview with the tape recording began, an effort has been made to create a friendly atmosphere and interaction, as a part of the participatory observation. During the interaction, they gave me a lot of insight by telling me what happened in their lives even though I never asked.

But when I started the formal interview using tape recorder as I planned to do, things started to be different. Since we were getting along and it was not the first meeting, it was not difficult to detect that they were acting in a different manner than what I had seen before. Their postures became stiff, their voice became tense and they were very selective in their wording. The flow of the conversation was frozen because they were being very careful in trying to choose the most appropriate word for the record.

The words and the sentences used to discuss the issue were in terms of normative discourses of HIV prevention. For example when answering to the question do you know how you became infected? The answers were:

*... It is known that HIV is transmitted through contaminated blade and needles from mother to child and through sex with out condom. I became infected through the third mode of transmission; sex without condom.*

Mulatua

*...My husband was not using condoms so I became infected...*



Mitike

There was no life in the conversation and their expressions were limited to explaining their situation in terms of *failure* to practice the prescribed protective practices. So after trying three interviews using tape recorder, I decided to stop the tape recording and started taking notes while doing the dialogic interview. After I stopped tape recording the situation improved and it became possible to have a conversation that was more like a normal conversation. The women were able to use words that they use in day to day conversation to explain their situation and became more focused on their individual experiences and challenges.

## 2.5 Conversation on sex across generations

While preparing the interview guide, the plan was to conduct the interviews according to the list of issues/items in the interview guide with all women who will be interviewed. It went well until I started talking to the three middle aged women. It was not easy to ask all questions because they were revolving around a very sensitive issue; especially those questions related to *sexual safety, pleasure and danger* were the most difficult ones. I was so shy to the extent that I could not utter the words and ask the questions. I was not throwing the questions in the manner I did with the other women, rather I was waiting for them to mention something that I could base my question on. As a result of this, the dialogic interview with the middle-aged women took much longer time than the dialogic interview with the younger ones. I had been talking to women of the same age in Norway and I neither had a problem in raising any of the questions nor did I feel shy to ask questions related to *sexual safety, pleasure and danger*.

My experience while having the dialogic interview with the middle aged women on *sexual safety, pleasure and danger* shows the triadic nature of the interview process: the interviewee, the interviewer and the topic of discussion in this case discussion of sexual relations.

Discussion about sexual relations between generations, like other social cultural phenomena, is governed by codes for interactions that are socio-culturally defined and shared among a group of people. In the Ethiopian culture, discussion of sexual relations between the generations has always been a problem. This has been reflected in my work when I felt shy to ask questions related to *sexual safety, pleasure and danger* to women who were not in my generation which of course shows that the internalised cultural codes for discussion of sexual relations between generations were in operation in the interview situation.

From this experience I have learnt that, just as there are situations that make the research work easier because I speak the language and I am doing it in my country, there are other situations that make it more difficult for the same reason.

## 2.6 My position as a researcher

My position as a researcher could be described as an informed outsider; outsider because I am not HIV positive, but informed because I am an Ethiopian woman who knows the way of life and share cultural values with the women; associate member of Tesfa Goh, and I have been working with HIV positive people in a hospital setting both as care provider and counsellor. Before I left for the Master's study in Norway, I had also been working in a Leprosy control, training and rehabilitation centre, where I was counselling newly diagnosed leprosy patients that were in a similar situation due to the stigma associated with having leprosy in Ethiopia.

From the two contrasting metaphors *miner* and *traveller* used by Kvale to illustrate the research interviewer's role, I have tried to take the role of the traveller. In the miner metaphor knowledge is understood as buried metal and the interviewer is a miner who unearths the valuable metal. The alternative traveller metaphor understands the interviewer as a traveller who explores the many domains of the country as unknown territory with maps, roaming freely around the territory. The traveller may also deliberately seek specific sites for topics following a *method*, with the original Greek meaning of "a route that leads to the goal". The interviewer wanders along with the local inhabitants asks questions that lead the subjects to tell their own stories of their lived world and converse with them in the original Latin meaning of *conversation*, "wandering together with" (67).

## 2.7 Ethical consideration

Before commencing the study formal license was secured from the concerned bodies: The Medical Ethical Committee of Region 14 Health bureau, The Oromia Regional Health Bureau in Ethiopia and the Norwegian Ethical Medical Committee (NEMC) in Norway.

Formal communication has been already established with Tesfa Goh Ethiopia Addis Ababa and Nazareth branch offices during the proposal development process. A letter of acceptance and approval was given by the organisation to conduct the study before I began the study.

The research protocol and the interview guide were submitted to the Norwegian Ethical Medical Committee (NEMC), The Medical Ethical Committees of region 14 and The Oromia Regional Health Bureau. Data collection began after I got clearance and permission from the three committees.

The purpose of the study was explained to the participants verbally and the written form was given to them with the consent form. In the verbal explanations as well as in the consent form the participants were first informed about the nature of the study and as it will revolve around their very personal life experiences. Second, they were informed about their right to refuse to participate in the study or withdraw from the study along the process any time they want and as they will not be obliged to participate or give their reasons for not doing so. They were also informed as refusing to participate or withdrawing from the study will not have any consequences on them and as the information they provide will be treated with confidentiality and that their names will not be mentioned anywhere.

For the purpose of respecting individual rights and dignity, the respondent's names were not mentioned in the field notes and in the thesis. Instead nick names or names they wanted to be called were used. Informed written consent was obtained from participants for their response prior to the data collection process. Information given by participants and their identity was treated with confidentiality and used solely for the purpose of the study.

After the completion of the research establishment of a long term contact was discussed and contact address was given to the participants of the study to use it if they want to continue the discussion or need counselling, when I go back home. For those who wanted to write letter, postal address was given and contact address was also given to Tesfa Goh Addis and Nazareth branch offices.

## **2.8 Analysis, Analytical concepts and frame works**

At the end of each interview, summary notes were written and attached to each field note. The data analysis process started simultaneously with data collection. After the data collection process was completed the already started data analysis process continued and the data was thematized and analysed.

The analytical frameworks used for this study were the scripting theory and the new conceptual frame work developed by Parker and Aggleton for understanding HIV/AIDS related stigma and its effects (23). The frameworks guided both investigation and analysis for this study.

### ***Scripting Theory***

Scripts are essentially metaphors for conceptualising the production of behaviour in social life. According to the scripting theory, scripting will occur at three distinct levels for behaviour to occur. These three distinct levels are: the *general* cultural scenario which refers to conducts that are embodied in the cultural narratives which guide or instruct for all conducts at the collective level; *Interpersonal scripts* i.e. the structural patterns of interaction in which individuals as actors engage in every day interpersonal conduct and *intrapsychic* scripts which, refer to the plans and fantasies by which individuals guide and reflect up on their past, current or future conduct (68).

### ***Sexual Scripts***

Sexual scripts are concepts of the scripting of behaviour applied to sexual activity and they occur at three levels: the general cultural scenario, and the specific interpersonal

and *intrapsychic scripts*. *Cultural scenario* provides instruction at cultural level about how persons should and should not behave sexually. *Interpersonal scripts* represent our definition of the immediate social context. They refer to the organisation of mutually shared conventions and representation of the self and the implied mirroring of the other that allow two or more actors to participate in a complex act involving mutual dependency. *Intrapsychic scripts* refer to the motivational element that produces arousal or a commitment to the activity and the private world of wishes and desires that are experienced as originating in the deepest recess of the self must be bound to social life: the linking of individual desire to social meanings (68). Sexual scripts allow women and men to engage in interactions with some degree of orientation and expectation about what will or what will not occur (17).

The other framework used for the analysis of this study especially the issue of stigma was the classical theory of Goffman on stigma and the new conceptual framework that conceptualises AIDS stigma and stigmatisation as intimately linked to structure of power and reproduction of social difference. According to this framework, stigmatisation functions at the point of intersection between culture, power and difference, hence, stigma feeds, strengthen and reproduce inequalities of class gender and sex (23).

## **2.9 Dissemination of findings**

Ways of dissemination of findings were discussed with the organisation and preliminary findings of this study were communicated with Tesfa Goh. The full finding of this study will be communicated to governmental and non-governmental organisations, institutions or individuals that have direct or indirect input in the study

and in the prevention of HIV/AIDS in Ethiopia, other interested groups and my colleagues in Norway.

This can be accomplished through submission of reports, presenting findings at appropriate meetings, seminars, and workshops and it can be published in scientific journals.

## **Chapter III**

### **Country profile**

Ethiopia is a Federal Democratic Republic situated in the horn of Africa covering about one million square kilometres, comprising nine national regional states (Oromya, Amhara, Southern Nations and Nationalities Peoples, Tigray, Somali, Afar Benshangul Gumz, Gambela and Hareri) and 2 city administrative councils (Addis Ababa and Dire Dawa). Ethiopia has a multi-ethnic society with approximately 100 Nations, Nationalities and people (3). The Ethiopian legislation is bicameral parliament and the judicial system is divided into Federal and Regional courts.

Ethiopia is among the most populous countries in Africa, ranking third after Nigeria and Egypt. Fertility rate is high (5.9) and 46 % of the population is under 15 years of age (69). Life expectancy at birth is 51 years for male and 53 years for female and only 4% of the population are over 65 years (70). Men account for 50.3% of the population and women account for 49.7 % (69).

The per capita Gross national product (GNP) is estimated at 100 USD. Out of the nearly 67 million inhabitants 85% percent live in rural areas and rely on traditional agriculture for survival. Primary education coverage (gross enrolment) is 57% but a high proportion of the population is illiterate. Health service coverage is very low (51%) (3).

With Regard to religion, the major religions in Ethiopia are Christianity and Islam and are followed by 62% and 32% of the total population respectively. Traditional religion followers account for 5% of the total population (69).

### **3.1 Broad National HIV prevention efforts**

The national HIV/AIDS control effort in Ethiopia started with the establishment of the National HIV/AIDS control Program (NHACP) by the Ministry of health in 1987. Ethiopia launched a national HIV/AIDS policy that advocates multi-sectoral approach in response to the epidemic in 1998. The overall goal of the national policy is to implement successful programmes to prevent the spread of HIV/AIDS, decrease vulnerability of individuals and communities to HIV/AIDS, care and support for people living with HIV/AIDS reducing vulnerability, stigma and discrimination and the adverse socio-economic consequences of the epidemic. It also provides a platform for protecting the rights of people living with HIV/AIDS (3, 12).

The former NHACP was replaced by The National HIV/AIDS Prevention and Control Council (HAPCO) constituted in March 2002. HAPCO was established to mobilise multi-sectoral and grass root efforts to fight the epidemic. It is the executive arm of the National HIV/AIDS Prevention and Control council which is a multi-sectoral body chaired by the President of the Republic and comprising all government ministries, regional presidents, NGOs, religious organisations, associations of people living with HIV/AIDS (PLWHA) and prominent individuals. It is led by an executive board and comprises 8 ministers and several representatives of the civil society and the private sector (3, 12).

### **3.2 Situation of women in Ethiopia**

The situation of women in Ethiopia is difficult and they belong to the economically and socially deprived society with respect to health, education and social mobility.

They bear the brunt of familial responsibilities even as they live in conditions of extreme poverty. Majority of women in Ethiopia are unemployed and have no access

to land or credit institutions in either urban or rural area. Education wise majorities of women are illiterate. Girls' enrolment accounts for only one third of all school enrolment. 75% of women aged 15-49 are illiterate compared to 47% of men (71, 70).

Very few women are in decision making positions in Ethiopia. For example, in The Federal House of Representatives women occupy only 7.6% of the seats. From 128 members of the Federal Council, only 7 are women (72). There is only one female full minister at Federal level out of 16 men and there are 5 female ministers at a state level.

Women also suffer from harmful traditional practices such as female genital mutilation, early marriage and abduction (71).

Female genital mutilation is among harmful traditional practice institutionalised in Ethiopia. It is believed to decrease a woman's sexual desire and thereby safeguard her virginity (73). In Ethiopia female genital mutilation is widespread and four out of five women having been circumcised (70). The type of genital mutilation varies from region to region but all 4 types of circumcision are performed in Ethiopia (74).

Early marriage is also a common practice in Ethiopia. Girls are often married before the age of 15. In 1990's from ever-married women in Ethiopia 34% were younger than 15 years at first marriage. But the median age of marriage has risen slowly over the last 20 years. For example, the median age of marriage has slowly risen from around 16 years among women age 30-49 to 17 years among women aged 25-29 and 18 years among women aged 20-24 (75,69). Early marriages are usually arranged by parents in compliance with tradition motivated to some extent by the desire to ensure a girl's virginity and hence safeguard the social standing of the family (76).

Abduction is another common cultural practice used to take a girl as a wife by force. For example, according to a study done in Oromia region, the largest and the most populous regional state in the country, one in five women married by abduction. Out of these abducted women 60% were abducted at the early age less than 15 years and 93% were abducted before the age 20 (77, 78).



Women also suffer from lack of access to health service. For example Maternal Mortality Ratio is very high, according to The Ethiopian Ministry of Health Health and Health Related Indicators it is between 560-850/100,000 live births (79).

### **3.3 Associations of people living with HIV/AIDS**

Nationally there are two major associations of people living with HIV/AIDS: Tesfa Goh, and Mekdim (3). Mekdim is another organisation of people living with HIV/AIDS founded by HIV positive people and AIDS orphans' in 1997. Its objectives are providing HIV/AIDS education through different IEC activities; provision of home based care and providing ongoing individual and group counselling. It grants full membership for interested individuals and organisations without putting their HIV serostatus into consideration. Mekdim Ethiopia has 420 members.

## **Chapter IV**

### **Ethnographic Description**

The complex and multifaceted nature of the phenomena under study requires understanding the way of life and the contexts in which the life of majority of Ethiopian women, which of course includes women in this study are situated. Hence, in order to meet the demand I have chosen to present the ethnographic context of the

participating women by a way of a constructed case. This choice was made in order to show the shared day to day life of most Ethiopian women cutting across ethnic, religious and occupational boundaries. It was also used to inform the normal and normative; the ideal and the non-ideal way of life and expected roles of Ethiopian women in different stages of their life cycle trajectory. Such information helps to contextualise the women's narration and understand their HIV related dilemmas in their day to day life. It is also intended to show contribution of the way of life and the social institution and institutional structures made in raising moral questions and creating dilemmas that might have exposed the women to HIV infection and the stigma that follows their HIV positive serostatus.

These descriptions are abstracted from the collection of stories of the participants of the study and many other sources. I have constructed this ethnographic description using folk tales written about a moral woman from the book "*Enkilf leminae*"; abstractions of narration of the women in this study; media discourses about sexuality, HIV/AIDS and moral personhood and on going radio play "*yeken kignet*"; church teachings about HIV/AIDS, premarital sex and moral personhood; narration's of old women (in their 70's) about life in their generation and my own knowledge and experience as an Ethiopian woman

### ***The daughter***

My name is *Ennat*, and I am the daughter. I call my mother *Emmamma*, my father *Abbabba* and my grand mother *Ayatea*. I grew up in Addis Ababa with my 3 brothers

and an uncle in a 2-room Kebele house<sup>2</sup>. I am the only daughter in the family. Now I am a grown up woman with a good job and adequate income to support my self.

I know and feel that our house is overcrowded. Two rooms are not enough for 6 people. There is no space at all and I always dream about having my own place with my own space. I know that a few women started to leave their parent's house and live in their own house but most people neither accept nor support it. My parents would not approve it either and are among the majorities who are against it. They say that it is not the norm for a woman to leave her parent's house before she got married. So they will not approve my interest in having my own place unless I am married. I do not want to discuss the issue with them because I know that they would not agree. But I envy my younger brother who was allowed to have his own house without any objection just *because* he is a man.

It was not easy to reach where I am now and I know how hard my family worked to help me achieve my goals and make my dreams of becoming an educated woman true. They gave me a chance to get education and supported my study and schoolwork in anyway they can. Now it is my turn to try to make them happy.

When I compare myself with my mother, I think I am lucky to be born in this generation. But this does not mean my generation does not have problems but still I think things are getting better.

My mother (*Emmamma*) told me that she was born in a rural village and she was the first born in a family of five children. Her grandmother from her father's side and her two older uncles were also living with them. Their house had two compartments; one for the cattle and the other for them to live, cook, eat and sleep.

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<sup>2</sup> A government owned house rented to the public with a cheap price

She grew up listening to folk tales; during daytime from the village elders who usually sit under the big trees and tell stories to the village children, and at night from her grandmother. Every night after dinner all the children in the family and sometimes her parents sit around the fireplace to listen to her grand mother's stories. The stories were not just simple stories to be told but there was a lot of moral in them and this was how she learnt what a good person, a good husband, a good wife, a good mother a good father, a good daughter and a good son should behave.

*Emmamma* was not more than 7 years old when she started to help her mother in domestic work by fetching water from the nearby spring and collecting firewood.

There was not much to save but there was enough to feed the family. She told me that her father was a hard working farmer and a respected member of their community for his hard work, his dedication to his family and his religion.

According to *Emmamma* my grandmother was a good wife to my grandfather and a good mother to *emmamma* and her other children, whom almost every one in the village loved and respected. *Ayattea* wakes up early in the morning even before sunrise and never goes to bed until she makes sure that everybody is feed and asleep. The whole household responsibility lies on her: she has to clean the house; fetch water; collect firewood; cook food; wash clothes; bring lunch to her husband who works in the field; feed the domestic animals and a lot more.

*Emmamma* told me that Sunday morning was the only time that she used to see her mother relaxing a little bit. On Sunday every member of the family used to go to church as early as 6 o'clock in the morning for prayer. The churchyard is not only a place for prayer but also a place to meet friends and fellow parishioners and discuss problems in the neighbourhood and community. When I had asked her if women participated in the discussions, she smiled at me and said, "Back then, this was men's business." But I still think it is the same in my generation when it comes to making decisions. She told me that women chat a little bit about issues like, the cattle, their children's health, who is going to get married, who missed the church service with friends and hurry to return home before their husbands and to prepare *Yesenbet Kurs* (the Sunday breakfast).

There was no formal school in the village and the family could not send all the children to the school in the near by town so they decided to send the boys. Hence, *Emmamma* did not get a chance to go to school.

She grew up playing with neighbouring children until she became 10 years old. Things started to change after she became 10. She is not allowed to go out and play as she used to any more because she has got a lot to learn about cooking and house keeping. Men had already started asking for her hand in marriage so she needs to learn things faster and it is *Aayattae's* responsibility. If she is not trained in doing the domestic work properly before she gets married, she will be ridiculed. But it dose not stop there it affects the family name too. *Ayateea* will be blamed for failing to bring up her daughter properly.

After that *Emmamma* told me how she missed playing with her friends and how much she envied her brothers who were allowed to go to school and are allowed to play with friends. She could not see her friends as often as she used too; she met them only in limited occasions when they go together to the spring to fetch water. They inform her about what is happening in the village. Other possible places for *Emmamma* to meet her friends were weddings in the village and *Gebeya*<sup>3</sup>.

When there is going to be a weeding in the village, girls and boys start to get together and sing and dance every evening at least starting one week before the weeding in the presence of the family of the bride to be. They were also allowed to attend the ceremony on the weeding day.

She told me that she was not supposed to talk to boys and to avoid relationship with men so she only chatted with girls. She also told me how difficult it was back then if a girl is seen standing with a young boy or a man and talking to him because people could start to talk about it. They even could tell to the family of the *misbehaving girl* so that she will be punished. I do not think it is a problem that was there and has gone

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<sup>3</sup> Open market

now because girls in my generation also worry about what other people could say if they find out about their love relationship.

*Emmama* told me that *Gebeya* serves multiple purposes beyond buying and selling goods. It is also a place to choose *yekenferwodaj*<sup>4</sup> or possible future marriage partner. Hence the weekly market day was a day which every one used to come wearing his/her best clothes and looking his /her best.

She got married before her 14<sup>th</sup> birthday and every thing had been arranged by her family. Nobody told her that she was going to get married. It was a week before the wedding day that she was told that she would get married after a week. No body explained to her what was going to happen or what she was expected to do with her husband when they took her to *chagulabet*<sup>5</sup>. On the wedding night she slept with her husband and her husband's best men returned to her parent's home early in the morning to tell her parents that she was virgin.

Her husband (*Abbabba*) was the son of her father's best friend. He was 19 when they got married and had gone to school away from home living with his aunt but quit school after finishing primary school because there was no junior secondary school in his aunt's village.

After living in the village for a while, *Abbaba* decided that they should move to town. He found job in the factory and they started living near by the factory in a *Keble* house that has got two rooms; the same house that we are still living in now. She gave birth to three children two boys and me. Her aunt's son from the rural village moved to our house to live with us and get a chance to go to school.

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<sup>4</sup> A lover ( the love relationship between a young man and woman where the body contact is limited only to kissing )

<sup>5</sup> Special room prepared to the newly weed.

When she compares it with the rural life, *Emmamma* tells me that life is much better to be in town. When I asked her why she thinks so, she said, “There is electric light in town; I do not need to walk long distance to fetch water or to collect firewood; my children go to school. So what more could I ask for”?

*Emmamma* tries to make everybody happy. Taking care of the household business has always been her responsibility but I sometimes help. She always gets up early in the morning to start cooking, cleaning, fetching water from the common water pipe in the village, shopping and taking care of every body’s needs.

At least once in a day she has to make coffee and invite her very nearby neighbours to have coffee. They will also invite her for coffee later on the day. This is the only time for the busy ladies to take a break and have a coffee chat.

She is also member of the local *Iddir* (a community funeral club). When someone from the neighbourhood dies, the village women take turns and cook food and make coffee to the family of the deceased and those who come to pay their condolences. This is also a place for people in the neighbourhood to sit together and discuss many issues from personal to national because members of the same *Iddir* also belong to the same neighbourhood and most of the time to the same religious congregation.

She spends much more time in the *iddir* than she used to because a lot of people are dying especially young ones. With the new disease AIDS people are falling like leaves and *iddirs* are facing financial problems. It was also common to ask the family of the deceased about the cause of death but it is not easy these days because people do not want to answer this question.

She goes to church every Sunday morning wearing her long dress and *Netela*.<sup>6</sup> She tries to take some thing for the beggars that sit around the church because this is what a good Christian should do.

Now she can at least take something for them because things are better and I am supporting the family. But I remember what she used to tell me when I was a child and when there wasn't extra food that she could take to church; how things could have been different if she had been educated, if she had a job, if she had...

She used to take me to church every Sunday because she wants me to grow up being a fine educated religious lady. Now I go to church alone or with friends. When I was a student I used to go to church after school; after I got a job I go there after work. But still it makes her proud to walk to church with me.

In the church we learn about moral personhood and how a good Christian should behave. My Muslim friend tells me that they teach the same thing in the mosque and say that this it is a duty of a good Muslim. They teach about sexual abstinence until marriage. Now a days they also teach about HIV/AIDS.

They teach about the need to pray to God to take away this *meksefeft*<sup>7</sup> that we have brought on ourselves by sinning .They teach how we can prevent ourselves from this disease by obeying His commandments of abstaining from sex until marriage and avoiding fornication and adultery. They also teach as taking care of people who have AIDS is a duty of every Christian who obeys the commandments of God.

I spend my spare time with friends. We are from different ethnic and religious groups but we do not consider it as a problem. It is not only me; *Emamma* and *Ababba* have also friends from different religious and ethnic groups too.

*Emmamma* tells me often how people ask her about my weeding day whenever she goes to a wedding in the neighbourhood and all her dream is to see my weeding day. She is waiting for that day too because she believes that whatever educational achievement a woman has, unless she is married and have children then her life is meaningless. Now she is 50 and all her children are grown-ups so she thinks that it is time to concentrate on her spiritual life praying and fasting. I never heard my parents talking about their sexual relationship or their love for each other in our presence.

So I used to think that these kinds of issues are not to be discussed between parents and their children. In our family, the only person whom I heard talking about her love life is *Ayatea*. I can see my parent's uneasiness whenever *Ayatea* starts to talk about

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<sup>6</sup> A traditional shawl made of cotton.

<sup>7</sup> Equivalent to the English term plague as described in biblical stories



her past love life. She talks about her *yekenferwedaj* who used to walk with her when she goes to the village spring to fetch water and help her to carry her *Ensira*.<sup>8</sup> She also talks how beautiful she was and how young men used to follow her wherever she was going. She also talks about the kind of limited freedom her generation has especially in choosing a marriage partner.

She told me that in her times a woman could choose her *yeknerwodaj*, although the question should come from him first, but not her husband. This is because it is her family who is going to decide whom she should be coupled with in the end. *Ayate* also told me how she met her *yekenfirwodaj* in the market place and how lucky she must be to end up marrying him. Most village elders do talk about their love life in the past too, women with women and men with men.

Although not getting married and living independent life is unacceptable here, I can see that things are changing when it comes to marriage arrangement. At least I can choose whom I am going to marry.

I have a boyfriend and we often talk about getting married. For the time being I am doing my best to keep this issue silent. I think *Emmamma* suspects as I have a boyfriend but we never talked about it. Neighbours should not find out about it too. If they find out, they could start talking. I know that my parents want me to remain virgin until I get married but I have already started sexual contact. I think they do not understand how difficult remaining virgin could be when you grow older because they used to get married when they were very young. I do not support the idea of early marriage but I am trying to understand the reasons why they do not understand the difficulty.

I am a woman and the first born in the family so my parents want me to have a big party for my wedding. Bridal gift is also the important part of the ceremony that is believed to indicate the respect that the husband to be has for his fiancé and her family. I am supporting my family and my boyfriend is doing the same so we do not have that much money to throw a big wedding party.

When I think about getting married, it is the *serg*<sup>9</sup> party that we are expected to prepare and its expenses that worry me a lot. It is not an easy thing. Even with the

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<sup>8</sup> A pot made of clay and used to carry water usually on the back.

<sup>9</sup> Ceremonial marriage

smallest possible wedding party, at least we have to invite 100 people. So we have to wait until we save enough money but the relationship continues just as it is now.

## **4.1 Social relations and institutional structures**

The story as told shows a number of social relations and institutional structures that show the life and social responsibilities of Ethiopian women in their day to day life in their social setting. These social relations and institutional structures will be considered here in greater detail.

### ***Gender relations and role***

In Ethiopia Gender preference begins before children are born and continues afterwards. Boys are given special favour and are allowed much more freedom and girls are expected to be shy and quiet. Gendered division of labour is also introduced early in childhood where boys are trained in outdoor activities and girls are trained in domestic work and caring for children (71).

It is considered traditional in Ethiopia that men and women have clearly defined different roles. Men are responsible for providing income for the family and deal with family contact outside the home whereas domestic work and caring for children is women's domain. Even when women earn an income and equally play the provider role, this traditional role persists and handling domestic issues and caring for children in day to day basis is still taken as a woman's responsibility. There is a slight change in urban areas in the way the traditional gendered division of labour is practised; men are at least participating in the day to day care of children. But still in majority of the population day to day care for children and household chores are women's responsibilities.

## ***Motherhood and fatherhood***

In all cultural groups in Ethiopia motherhood is given top attention and a woman's status to certain extent is related to the number of children she has given birth to (65, 57). This is reflected in the shower of gifts that she receives and the love and care she enjoys from immediate family and neighbours when she gives birth. She is given the best food and is exempted from work for days or weeks (65). Due to the great value given to having a child that will inherit the family land and continue the family name, motherhood enhances a woman's marital security and insures her continued marriage (57). Taking care of children is part of motherhood, which is considered to be a woman's business.

Fathers are not most of the time as close as mothers to their children. Their traditional role focuses more on providing adequate income to support the family and the disciplining of children. Fathers more often have closer relationship with boys than girls since they are taken responsible for their socialisation. Fathers especially in the rural areas have a power to chose and give the final decision concerning their children's marriage partner but more their daughter's marriage partner.

## ***Religion and religious institutions***

Ethiopia is a religious country and religion is a secured and accepted element of life, which influence meanings and practise in every day life. The major religions in Ethiopia are Christian and Islam. Among Christian's 82% are Orthodox 16% are Protestants and 1.4% are Catholic (69).

Religion is believed to be determinant of moral behaviour in general, which of course includes sexual norms. Hence religion and moral are taken as two sides of a coin and religiosity is taken as a moral standard. For example regular church attendance is taken to be a very good indicator of one's moral personality.

The churchyard, in the Ethiopian context, is not only a place to pray and worship but it is a meeting place to discuss community problems, a shelter for the homeless and a place to settle disputes and arbitrate family issues. Residents in the same area usually go to the same nearby church and belong to the same congregation and are members of the same moral community.

Gender inequality is institutionalised in major religions in Ethiopia. For example in the Ethiopian Orthodox Church men and women have separate places of worship. Some holly places are prohibited for women and even female animals were excluded from the church grounds. Islam segregates women even within the household, supposedly to protect them from harm (80).

Religious institutions are very powerful institutions and their leaders are respected and trusted by fellow parishioners. These institutions are involved in care and support of individuals affected and infected by the HIV epidemic since the 1990's. However they remain largely opposed to condom use (81, 82). Although religious explanation given about the causes and purposes of HIV has contributed to HIV/AIDS stigma and discrimination, their acceptance and thrust might also make religious institutions and their leaders potentially suitable to address the stigma associated with HIV/AIDS.

## ***Marriage***

Marriage in Ethiopia is a social relation between a man and a woman in monogamous marriage or a man and women in polygamous union. From a social perspective it involves law and material matter. There are many ways of institutionalising marriages in Ethiopia but the most common ones are *serg* (ceremonial marriage), *k'urban* (Communion marriage), Muslim religious marriage, *semanya* (civil marriage) and *t'ilf* (marriage by abduction). These categories of marriage however are not rigid. For example *semanya* (civil marriage) or *serg* (ceremonial marriage) could follow marriage by abduction (83). Majorities of marriages in Ethiopia are monogamous. Polygamous union accounts for 14% of marriages in Ethiopia (70). The role of marriage in regulating sexual relationship is given high value. This is reflected in the disapproval and stigmatisation of extramarital sexual relationships (will be discussed further in the next chapter).

In traditional Ethiopia, marriage is seen as a union of the families of the bride and the groom and most marriages in rural Ethiopia are family arranged. Marriages contracts were made for the mutual interest of the families involved. Romantic love, as understood in the west, was not conscious consideration in marriage arrangement (73). Although it is a family arrangement, boys have some choices at least in suggesting whom they would like to marry. The situation is changing in urban areas and men and women are allowed to choose whom they want to marry based on romantic love.

## ***Iddir***

*Iddir* is an indigenous informal welfare association, with the primary function of helping in arranging funerals, defray the cost and prepare a place to sit and food to eat for the family of the deceased and those who come to pay their condolences. Members of *Iddir* are obliged to contribute to common fund and to attend funeral of the member and members of his family (84). *Iddir* especially provides forum for women whom otherwise have no frequent chances to meet and discuss social problems.

Usually people who come to pay their condolences sit next to the family members with the same sex. Women sit next to the female family member and men sit next to

the man in the family. This provides forum for both men and women to discuss social problems like HIV/AIDS in their own circles.

This social welfare association is among the institutions affected by the HIV/AIDS epidemic. Many *Iddirs* are facing financial crisis because of the increased expenditure of money required to cover the funeral expenses of members or families of members dying from HIV/AIDS (81).

*Iddir* cuts across ethnic, religious and occupational boundaries and there is high degree of commitment, participation and dialogue between members. Due to this it is among the community based organisations that has great potential to serve as a spring board in HIV/AIDS prevention efforts including stigma reduction and provision of home based care for AIDS patients (84, 81).

## **Chapter V**

### **Discussion**

#### **5.1 Moral order and sexuality**

Moral is a difficult concept to define. For some it is expressed in terms of following the do's and don'ts. Others express it in terms of good and evil; the good representing the moral and the evil representing the immoral. Others express it in terms of virtue. One thing that can be agreed upon though is that moral is concerned with the rules of the right conduct in a given context at a historical period in time.

Moral like other social phenomena has order and this order is one of the control mechanisms of society which maintains social order. This mechanism works through the use of dominant moral values and standards against which the legitimacy and character appropriateness of one's action is evaluated and subsequently categorised as either moral or immoral.

Morality is a culture specific construct and moral values and scripts reflect what is considered moral or immoral in a given cultural context. Hence, although more often people tend to think so, moral values and scripts are not universally applicable. In other words the variation of moral values and scripts from culture to culture reflects that those values that cause categorisation of an attribute or a person as immoral are not inherently immoral but derive their moral values from the specific cultural meanings (85).

Moral standards are applied in evaluating diverse social areas and many social phenomena. Human sexuality is among those social phenomena that has been continuously evaluated from a moral point of view and consequently categorised as moral or immoral (86). It is not surprising therefore that sexually transmitted diseases in general and HIV/AIDS in particular are associated with moral disorder.

Though the association of HIV/AIDS with moral issues is almost universal, since morality is a culture specific construct reasons for associating HIV/AIDS and moral issues also vary with cultural contexts. Hence, in order to understand the association made between moral disorder and HIV/AIDS in the Ethiopian context, it is necessary to understand what is considered a moral standard. For this purpose, pre-existing local beliefs, religious explanations, knowledge and moral values surrounding sexuality, and gender in the existing moral order in *general* and gender *specific* moral implications in particular will be properly considered.

## 5.2 Sexual norms in Ethiopia

Sexual relationship as a social phenomenon has norms and standards against which its propriety is evaluated and all sexual relationships are not accepted by society. Sexual norms usually reflect the idealised code of sexual behaviour and serve as a standard code of sexual morality against which sexual practices of individuals or groups are judged and labelled as moral and approved or labelled as immoral and rejected and stigmatised. Hence, understanding sexual norms is instrumental in understanding AIDS stigma as a mechanism of social control in preserving sexual morality in a given cultural context. It also helps in understanding difference and severity of the AIDS stigma that follows violation of the norms of sexuality in different segments of the population.

Sex has been described by sex and gender researchers as a resource with both symbolic and material value: as a source of sensual and emotional pleasure; as a necessary part of the production of offspring and/or as a means of acquiring social status, as a means of establishing personal relationship and broader social alliances e.g., through marriage (87).

This definition of sex applies to Ethiopian context also. However, in a country like Ethiopia, where marriage is almost universal and production of offspring is highly valued and associated with social status, the roles of sexual relationships as a means of establishing and maintaining other social relationships and broader social alliances through marriage and as a necessary part of production of offspring's is highly valued.

In Ethiopia, the socio-culturally-approved sexual relationship is heterosexual contact within marriage for the purpose of procreation. Many kinds of sexual practices are disapproved in Ethiopia and can cause stigma. Among these are premarital sex, extra marital sex, and homosexuality.

However, since the main focus of the study is the woman gender and the local epidemiology is heterosexual, only disapproved and stigmatised heterosexual relationships and those values in heterosexual relationships and their gender specific implications will be considered from the moral point of view. As described in the



earlier chapter, since religion is believed to be detrimental for moral behaviour including sexual norms, religious point of view will also be considered in relation to the moral point of view. For this purpose premarital sexual relationships and extramarital relationships will be discussed in particular.

### ***Premarital sex***

In many parts of Ethiopia, premarital sexual abstinence for both men and women is the ideal social standard and the recommended code of sexual conduct by both social and religious contexts. Ideal standards and practices are however two different things and their relationship to each other is indeterminate. Sexual practices change with changing society. With increasing age of marriage, diffusion of culture through education, mass media and other different routes, the culture of sexual abstinence before marriage is changing in urban areas. For example according to the results of a large comprehensive survey conducted in urban Ethiopia, examining young people's reproductive and premarital sexual attitudes and behaviour, about 50% of never married men (15-29) and 19% of the never married women (15-29) reported having sexual experience (88). Multiple research findings on young peoples sexuality in Ethiopia have shown falling age of sexual debut and increasing rate of premarital sexual involvement (89-91). The high morbidity and mortality from abortion complication and high prevalence of HIV/AIDS in the young people also indicates increasing rate of premarital sex (91).

However, the change in practice does not always show the change in view towards the ideal sexual standards or norms. Ideal standards could still continue to be standards even when practices are changing (92). For example in the above-mentioned study despite their practice both male and female respondents disapproved of premarital sex and idealised abstinence. In another study done in Addis Ababa, the capital city of Ethiopia, to find out the attitude towards premarital sex in the 15-29 age groups, despite their premarital sexual experience they idealised abstinence until marriage (73). Although their attitude was not in agreement with their actual practice, the survey result shows that premarital sexual abstinence is still valued, idealised and taken as a moral norm.

In the rural part of Ethiopia marriage is still arranged by family and sexual abstinence of girls until they get married is highly valued. This is indirectly reflected in the agreement of the girl's family to marry the man who abducted and raped her because the girl who has lost her virginity would be socially unacceptable for marriage to another man. Following the agreement, the abductor will be excused from being accused of his crime even though rape and abduction are criminal offences under Ethiopian penal law (77, 78).

Although premarital sexual abstinence of both male and female until marriage is the recommended code of sexual conduct in religious teachings and current health messages of HIV prevention, premarital abstinence is a gender specific expectation in Ethiopia. Premarital sexual relationship of women is disapproved and taken to be wrong in religious and cultural terms. However there are multiple discourses about male premarital sex. Religious and health teachings disapprove of premarital sex for both men and women but social discourses differ from religious teachings when it comes to male premarital sex. In social discourses men are believed to have a natural sexual urge that needs an outlet. Hence in practice they are not expected to abstain before marriage although it is believed that it would be beneficial for them for prevention of sexually transmitted diseases (73). They will not be

stigmatised for their premarital sexual experience and their sexual act will not be associated with their upbringing or their family name.

Men became sexually active long before marriage (70). Family or society does not inquire into a man's premarital sexual history unless it is in very special circumstances such as *qurban* marriage (communion marriage), where both partners have to be virgins.

For a girl the person who intends to have a relationship with her inquires about her premarital sexual history and in case of marriage the bride's family also inquire into it. It is targeted interest of a woman's family and future marriage partner (93).

Marriage in Ethiopian society marks a woman's first entry into sexual relationship and her premarital sexual abstinence is unambiguously defined by the presence of intact hymen (93).

To understand the meaning and implications of having premarital relationships for a girl in the Ethiopian context, one needs to understand first what premarital sexual abstinence i.e. being virgin means and its moral implications.

In Ethiopia the two words used to express virginity are *hig* and *kibrenitsihina*. *Hig* literally means "Law" and in this context refers to the moral code *higebahiry* which has the same meaning as the English term moral code. The question asked to a girl when one wants to find out whether she is a virgin or not is *hig alesh?* Which means have you abided by the moral law? (94). This shows how the issue of virginity is seen in terms of a moral question and used to assess the total personality of a girl. Virginity is associated with trustworthiness and losing one's virginity is considered indicator of weak moral fabric.

The other term used to describe virginity is *kibrenitsihena*. Literally, *kibir* means honour and *nitsuh* means clean, pure, unspoiled/unsoiled. *kibrenitsihena* Describes virginity in terms of purity and the presence of hymen is taken to show the purity of the girl and the honour that she and her family deserve. Virginity here is not a woman's property but a state conferred by/from her parentage nature up on her corporeal in the hymen itself. It is, therefore, not something the woman can dispose at own will but rather something trusted to her, entrusted to her, by others on behalf of whom she preserves, protects, safeguards. The fall is therefore betrayal of this trust, an embezzlement of the thing for which she is only the custodian.

Virginity of a girl is also important for the family's reputation because it is associated with good rearing and is considered to reflect the good moral fabric and values of the girl's family (93). Her family is affected by the insult that follows should she be found not virgin just as they share the reward of respect that results from her virginity. Losing virginity then is also understood as losing respect not only for oneself but also for ones that share the shame.

The high premium given to premarital sexual abstinence of girls is also reflected in the restriction of their activities around the homestead; prohibition of mixing with age mates of the opposite sex when they reach at the age when they are considered sexual beings and as mentioned before circumcision and child marriage are among the methods used to control a girl's sexuality and thereby preserve her virginity (71, 73, 7).

### ***Extra marital sexual relationships***

Extra marital sexual relationship is socially disapproved in most parts of Ethiopia for both men and women. However the gender based sexual moral double standard is reflected in extramarital relationships as well. Men's sexual experience in most cases is taken to be a result of natural sexual urge, which is beyond their control. This is a shared belief and view in many parts of the world and hence makes them less accountable for their sexual action (95, 96, 31). However the same action results in a serious moral question and brings shame for women. More over since they are expected to be the moral guardians of the uncontrollable natural sexual urge of men, women are also blamed for the believed mistake men commit. Sometimes women even take the blame for their husbands' extramarital affairs while men are excused. This is because their failure to satisfy their husbands' needs is taken to be the reason for husbands having extramarital affair.

## **5.3 HIV/AIDS and Moral disorder**

### ***Suggesting condom implying immorality***

*...when I suggested that we should use condom to my boyfriend, he got angry and said, "I am not an immoral person who sleeps around or go to prostitutes. So you should not think about using condom when you are with me". I told him that I do not mean any thing like that but he did not believe me...*

[Zehara, a 19 year old unmarried girl, describing her boyfriend's reaction to her condom use suggestion.]

Condom use is among the prevention practises recommended by HIV prevention programs. One of the major challenges that prevented some of the women in the study from practising "safe sex" with their partners was not lack of knowledge about the method. It was rather the association made between condom use and immorality.

In public health teachings, condom is described simply as a protective device.

However, for some of the partners of the women in this study, condom was a sign that mediated different meanings. As a sign it was also understood as an item that could reveal or disclose something about a partner's moral personality or suggest a weak moral fabric. For example, as shown above for Zehara's boyfriend her condom suggestion was understood as implying that he did not live up to the script of being a good boyfriend and accusing him of having immoral personality.

The associations made between condom use and immoral behaviour by partners of the women in this study could be the result of multiple factors. One of these factors could be the unfortunate coinciding of majority of sexual behaviours epidemiologically identified as "high risk" sexual behaviours, for which condom use is highly recommended, with socially disapproved sexual behaviours. In the struggle to control the HIV/AIDS pandemic, efforts have been focusing on a guiding concept of preventive medicine based up on epidemiological research findings. This guiding concept works by identifying attributes of those affected by disease and establishing associations between the disease and the various aggregate individual circumstances and attributes to construct risk factors, risk groups and, hence, likely candidates (96). The same guiding concept was used in HIV prevention efforts to identify high risk behaviour and construct high risk groups and likely candidates. For those identified as

“high risk” groups and likely candidates, condom use is highly recommended. As a result of this the public associates condom use with high-risk sexual behaviour.

Unfortunately, the majority of the practices that were identified as high-risk behaviour were socially disapproved and negatively sanctioned behaviours in moral and/or religious contexts. Hence, the women’s condom suggestions were interpreted as implying that one party is in the “risk group” and are subsequently read as categorising the party in question as immoral. This pattern of association emerged in numerous ways in interaction discourses.

*...when I mentioned condom use to my fiancée he said, why do we need condom? It is something that those who could not control their sexual desire and can not be faithful use. Are you saying I am one of them?*

[Birtukan, a 26 year old unmarried woman.]

Birtukan’s experience also shows the association made between condom use and immorality. However, the reason for the association made between condom and immorality in her situation might be the result of the information provided to the Ethiopian public regarding alternative HIV prevention practices and their placement in the hierarchy. In health teachings about ABC’s of HIV prevention i.e. abstaining, being faithful and condom use, condom is not described as an *option* among alternative prevention methods. It is rather described as the *last option* when the first two that is abstaining or being faithful are not possible. Since the first two are important indicators of a moral personality, condom is understood as a device that needs to be used by people with weak moral behaviour and thereby the women’s condom suggestion was taken to imply that a partner has weak moral behaviour.

The effect of the association made between HIV infection and moral disorder was not limited to being an obstacle to the women's efforts to prevent themselves from the infection. The manifestations of its effect also continued after they became infected as well. This was because it was taken as the sign of their immorality.

### ***The sign of immorality***

*... I do not like it and I wish they knew more, but at least I can understand people's reason if they refuse to eat with me or share cups with me. It is maybe because they did not clearly understand how the disease is transmitted and hence have fear of being infected. What is so hard for me to understand is why my morality was questioned and become a topic for gossip even by my close friends after they knew that I am HIV positive.*

[Misrak a 22 year old unmarried girl.]

*... people believe that you get AIDS because you have promiscuous sexual behaviour. It is said that it is a syndrome that is transmitted through "Liq yegbrsiga gengneunet" (undisciplined or unrestricted sexual relationship) so when you have AIDS it is like you got it because you have "liq bahri (undisciplined behaviour)"...*

[Genet a 22 year old unmarried girl who is living with her parents.]

Though the origin and the possible explanations varied among the women in this study their experience were the reflection of the association made between moral character and HIV/AIDS and subsequently the immorality the syndrome is believed to signify. The association is the result of multiple interwoven and interrelated issues. For example, Genet's explanation could reflect the possible contribution made by health education for the association made between the syndrome and moral disorder.

Starting from the period the first HIV/AIDS case has been diagnosed in Ethiopia; efforts made to control it have been focusing on providing information on the virus's mode of transmission and prevention methods to individuals and communities. Among the modes of transmission, mother to child transmission and transmission thorough un-sterilised surgical instruments and blood products have been directly translated to Amharic. Concerning the sexual mode of transmission, however, health information provided to the public has described HIV/AIDS as a syndrome transmitted through "*liq yegbresiga gengneunet*", which literally could be translated to either unrestricted or "wild" sex. "*Liq*" in Amharic language when used in

expressing ones behaviour refers to an act or behaviour that is not disciplined or does not follow proper order in the given context. The meaning understood by the public as described by the participant's of the interview core group as well as in the discussions with participants interacted during the exhibition was in relation to the second meaning "wild sexual behaviour" rather than unprotected sexual relationship. Consequently, women affected by the syndrome were considered to symbolise embody, and represent such behaviour.

More importantly, since sexual behaviour is more often considered to reflect the total moral personality of people, the effect of the immorality that the syndrome symbolises was not limited to the women's sexuality. Its broader effect was reflected when their total moral personality was understood as people with *liq bahri* (undisciplined behaviour).

### ***The sign of sin***

For some of the women the association made between the syndrome and their believed immoral behaviour might also be related to religious explanations given to the syndrome and its association with sin.

*... they teach that HIV/AIDS is the result of fornication and adultery so people generalise that all that have AIDS have committed such sin. HIV/AIDS is taken to be a sign...*

[Elisabeth, a 24 year old unmarried girl living with her parent's explaining the role of religious teaching in HIV/AIDS related stigma.]

*...God gave us the right rule of sexual conduct but we did not obey it. In His commandments it has been clearly indicated that adultery and fornication are sin. But we refuse to listen. What is the consequence? AIDS. To make us come back to our senses and obey His commandments...*

[A priest teaching fellow parishioner about the origin of the HIV/AIDS epidemic in one of the Ethiopian orthodox churches in Addis Ababa.]

As described in the above examples sited from the collected data, another possible reason for the association of HIV/AIDS with the moral disorder might be the religious understandings and explanations given about the cause and purpose of the HIV/AIDS pandemic.

The understanding of HIV/AIDS causation in Ethiopia has double layers. In this double layered understanding of causation, the religious explanations agrees with the biomedical explanation of HIV causes AIDS as well as the epidemiological explanations about contribution of the individual's sexual behaviour in acquiring the infection. This is reflected on HIV prevention teachings given to the public by religious organisations in Ethiopia.

However, beyond this level the religious explanation of the cause and purpose of the HIV/AIDS pandemic has another layer. Religious teachings about HIV/AIDS have been describing the pandemic as a consequence that resulted from the failure to abide by the moral law given by God/Allah towards human sexuality. Consequently, HIV/AIDS is understood as “*Mekseft*<sup>10</sup>”.

The accountability of individuals is, however, greater in the religious understanding. It could vary from bringing the disease on oneself and others by having *immoral* sexual behaviour to violating the rules of the super natural force (sinning) and thus being instrumental in bringing infection and suffering into existence. HIV/AIDS is

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<sup>10</sup> *Mekseft* In relation to HIV/AIDS, is expressed in the way the term Plague was used in Biblical stories (like in the story of Pharaoh ) to indicate the measures God has taken to punish those who went against His will to make them realise their mistakes, regret and return to His will. .



taken as the result of sin and the pandemic is taken to be the punishment for the immoral sexual behaviour human beings lead.

Since being a moral person in Ethiopia is more often associated with and described in relation to obeying the Commandments, the association made between the syndrome and sin might have contributed to the association made between the infection and the women's moral fabric.

### ***The trap of moral order***

The possible causes of the association made between HIV and moral order varied among individual women. However, one thing that was shared among the women in this study was their being trapped in the existing moral order. The existing moral order and the interwoven ways it works has trapped the women in this study in many ways and made their effort to protect themselves an insurmountable challenge.

*...I respect my parents; this is my duty as a Christian. My wishes were to continue my education and have a chance to lead my own independent life. But they are my parents, how can I go against their advice? I accepted the marriage because I wanted to make them happy and proud by being a good daughter to them...*

[Tsehay, a 32 years old widow and a mother of 2 children, explaining why she accepted the arranged marriage, which exposed her to HIV infection.]

Although more often people tend to think that moral issues that could be a challenge to women and influence their ability to protect themselves and others from infection to be specific to their sexual relationship for some of the women in this study it was not so.

The moral issues that became challenges to them were more than their sexual relations. They were reflections of the *general* moral rules guiding and governing interpersonal relationship although they were gendered in practice. Like Tsheay, for most women rejecting their moral scripts governing interpersonal relations and practising the suggested risk reduction or avoidance strategies was impossible because they were contradictory to the moral values they share with their family, friends and their community. They were trapped because opposing these values, whether it is

rejecting their religious duty or their moral obligation to their parents, in order to avoid risk of HIV infection could put their social relationship at risk.

The moral values in question are reflections of the existing social moral order and the scripts that work to maintain it. These general moral scripts have been accepted and internalised by the women in this study through complex and interlocking political, social and religious forces without the women's conscious recognition of the role these scripts could have in their lives. This is not ignorance; however, it is the result of the socialisation process. More importantly, being members of the community and sharing the culture, they also share the values and respect the moral scripts in their culture that define a good child/parent relationship in terms of obedience. Hence, more than the risk of social rejection and blame that they could face in their interpersonal relationship, violating these norms could lead to negative evaluation of self and consequently self-blame. This is because, for these women, no moral person exists without practising those moral scripts. This is not ignorance again but a consequence of being member of a society and hence sharing similar values.

The issues that created dilemma for some of the women in this study were not only moral questions considered *general* like parent to child relationships and obligations although gendered in practice. The challenges that some of the women in this study faced in protecting themselves from the infection were gender specific constructs and reflections of the complicated ways the existing gender order operates.

*...I know that I could protect myself from getting infected if I leave him. But if I do, I have to leave my children too. What is the meaning of my life if I could not be a mother to my children? The family arbitrators advised me to tolerate him for the sake of my children. They said, "This is what a strong and wise moral woman, who wants to be a good mother to her children and keep her family together should do."*

[Wudnesh, a 35 years old widow and a mother of 3 children, explaining why she continued living with her abusive husband, who is alcoholic, involved with multiple sexual partners and refuses to use condom.]

The experience of some of the women who shared Wudnesh's experience were reflections of the existing gender order and gender stereotypes that work through different gender based moral scripts (98). These moral scripts explain a woman's social worth in terms of her ability to fulfil her gendered division of moral labour. Moral labour here refers to the social organisation of moral script and responsibility on gender based division of labour that puts men and women into different moral labour category (99). The understandings and descriptions of a moral person for the women in this study varied with gender and were the reflection of the gendered division of moral labour. In most cases a man's moral worth is described primarily in terms of his own merits as honest, responsible, hard worker and then in relation to the contribution that he makes to the development of others by providing adequate income to support his family. Woman's moral worth on the other hand was described first in terms of the contribution she makes to the development and happiness of others or in relation to others. I would like to mention here that I did not mean that the primarily described merits of a man are not related to the contribution they make to the development of others. Rather here the attempt is to show the way the women described and prioritised the merits. A moral woman was described as obedient to her parents as a daughter; submissive and pleasing to her husband and a devoted mother to her children and in general as someone who puts other's needs before her own.

As a result of this some of the women who shared similar experience like Wudnesh were caught in dilemmas because of the contradiction between their expected gender

based moral script and the HIV prevention options they have. This was reflected in many interactions with the women in this study.

In a society where a woman's moral behaviour is expressed in terms of obedience, tolerance and putting the need of others before her needs, HIV prevention knowledge becomes a challenge to practice. They were forced to accept decisions made about their lives; decisions that made them a moral daughter and/or a moral mother in their cultural contexts and yet exposed them to HIV infection. Hence, the decisions that some of the women made were reflections of choices made in the absence of viable options.

### ***A choice without alternative***

*... I listened to the advice of the family arbitrators assigned by the court to handle our marital problems and continued to live with my abusive husband. I did so because they told me that I could not get custody of my children since I did not have enough income. Until the arbitrators decide that they could not handle the case and allow the divorce, he will not be forced to provide subsistence to our children. So, if I refuse to obey to their advice then there is no way for me to be with my children. If I could not be there for my children then there is no meaning to my life...*

[Misikir a 42 years old widow describing the legal system and interwoven socio-cultural contexts that deprived her from having a chance to protect her self from infection.]

The choices that some of the women who were in the same situation with Misikir made can be conceptualised as reflection of the existing gender order and its moral labour, which works through differential moral values that puts a woman's purpose of

life and moral worth in terms of the contribution that she makes for the development of others. In such a situation, to get a divorce or reject sexual intercourse without condom was not an option. This is so because it might prevent them from fulfilling the gendered division of moral labour of a mother in the Ethiopian context and thereby prevent them from becoming a moral mother.

As Misikir's situation reflected it, the influence gender inequality exerted on the women's lives was not limited to the gendered moral rules that governed their marital relationships or their relationships with their significant others at interpersonal level. The institutionalised version of the gender order and its operation to perpetuate and reproduce the existing inequality were also reflected by customs and existing institutional structures including the justice system which failed to handle their problems and provide them with protection. Hence, it is clear that in addition to the gender specific moral scripts and stereotypes, the choices that some of the women made were highly influenced by the institutional structures in their society which operated on the bases of gender inequality as reflected in the interwoven socio-legal systems that legitimatised their subordinate position in society. In other words, it is clear that their choices were not divorced from the context and history of their lives and the status and power they had in society.

Like Misikir, most of the married women in this study who had requested for divorce had no financial resource to support themselves and their children. This was aggravated by the former family law in Ethiopia, which until revised two years ago, establishes the husband's dominance in family relations (100, 101). In case of family dispute the husband would neither be asked to leave the matrimonial home for the wife and children nor will he be forced legally to provide subsistence until the case is

settled (96). Hence, the only option that women had was to live with their abusive husbands and continue to have sex without condom until the long divorce process is completed.

The revised family law abolished the law that establishes the husband's dominance in family relations and the mandate of the family arbitration system as a legally recognised institution for handling marital disputes two years ago. However, still it is not ratified by six of the nine regional states. Before the revision of the family law, when a husband or a wife files for a divorce, the court that accepted the application used to assign *Yebete zemed gubae* (family arbitration committee) to handle the problem. After a certain period of time, if the family arbitration committee could not help the couple in solving the problem it had the mandate to accept the request for divorce and legalise it.

*Yebete zemed gubae* was a traditional system that used to help couples to solve marital conflicts and thereby preserve the marriage institution. In the traditional family arbitration system, community elders (men) served as marriage counsellors and judges in settling marital disputes including approving divorce requests. There was no payment in cash or in kind for their service. However, through time this system lost its original function, although it retained its name, especially in urban areas. Slowly the community elders, who used to work in the family arbitration committee, got replaced by people who made working in such committees their job and the payment they get for their service their source of income and who do not share the responsibility that family elders used to have. Many women have been victims of this system because they have no financial resource to pay the committee for the service. The husbands who have the financial resource could use this resource

to prolong the divorce process and thereby make their wives, who have no other alternative, stay with them and force them to continue to have unprotected sex.

Like Misikir, the decisions some of the women made were very much influenced and became a choice without alternative because of socio-economic factors.

*... when he heard my decision to end the marriage and return to my parent's village from the family arbitrators, he said, "You should be patient and more tolerant if you want your marriage to work. I was young once and I have gone through the same thing. I am sure that your husband will get tired of everything soon and return to you. It was your mother's tolerance that kept our marriage for so long so you should try to follow her track." It is not easy to refuse a parent's advice even when you are grown up women like me I have been respecting his decisions all my life and I did not know how to start saying no... Besides, I did not have a choice...*

[Wudnesh expressing her father's reaction towards her divorce request.]

Wudnesh's situation and her father's reaction here reflect the interwoven factors at play: expected gender roles; economic status and daughter to father moral obligation.

Gender based moral scripts that exposed the women to HIV/AIDS risk usually vary with different stages of their life cycle trajectory. Before a woman got married she was expected to be obedient to her parents; after she got married her obedience is to her husband. But for some like Wudnesh, the obedience for both parent and husband continued even after they have started their own family. The continuity of her obedience and decision to continue to live with her abusive husband in Wudnesh's situation was not, however, only the result of daughter to father moral obligation. It was equally influenced by her economic and social status. Since she has no financial



income to support herself and her children, the only way to survive is to move back to her parent's place, which is impossible, unless her father supports and gives the permission for the divorce she had requested. Hence, her only choice was to stay with her abusive husband.

Wudnesh's experience as well as the experience of other women in this study shows that "safe sex" practice or avoidance of "sexual risk" is not simply a matter of individual's decision making that follows knowledge of preventive practices. Most women in this study neither lacked the knowledge of HIV prevention method nor failed to perceive the risk of HIV infection in their relationships. However, living in a setting where tolerance is taken as a quality of a good woman and intolerance of abuse is taken to be a sign of unwillingness to make marital relations work; it becomes difficult even to think that there is a way out. Even when the women make the decisions and attempt to get out of the trap their decisions were compromised by multiple economic and social conditions that their lives are situated. Nevertheless, the women were not exempted from stigma. This is because the infection they have is believed to symbolise moral disorder.

## **Chapter VI**

### **HIV/AIDS related stigma labelling and blaming**

#### **6.1 Stigma and moral order**

Stigma is a relational construct of an attribute that is deeply discrediting and that result in the reduction of a person or group from a whole and usual person to tainted one (102). It represents a construction of deviation from some ideal expectation. Hence, when an individual's or a group's behaviour is believed to be against moral expectations in the existing moral order; stigmatisation could be one of the powerful social moral order control and maintenance mechanisms of society. The social order maintenance mechanism works by stigmatising the person that is considered to have a behaviour that is against the existing social order with the purpose of maintaining social moral order.

The association of stigma with moral order has been established long before the HIV/AIDS pandemic. Goffman, in his classic work on stigma mentioned moral transgression as one of the three possible cases of stigma (102). Research on HIV/AIDS related stigma also reflected how the believed association of the syndrome with moral issues contributed to stigmatisation of people living with HIV/AIDS. For example Alenzo et al have explored the nature of HIV/AIDS related stigma by merging different types and dimensions of stigma identified by different researchers. According to these authors, among the causes identified for the HIV/AIDS related stigma were its taintedness by religious belief as to its morality and the believed association of its mode of transmission with morally sanctionable behaviour (85). Stigma in this paper refers to the co-occurrence of its components labelling,

stereotyping, separation, status loss and discrimination as defined by Link & Pheln (103).

Although the association made between HIV and moral order is clear, since stigma arises and takes shape in specific contexts of culture and power the consequences and social sanctions that follow the actual or believed violation of the moral order vary from culture to culture and along with one's social power and status. Hence, the level of stigma varies among different social groups.

Research done in different parts of the world has shown the difference in the level of stigma men and women encounter and the severity of the stigma that women experience. For example, throughout central and Southern Africa and Southern Asia women have been mistakenly blamed for transmitting the disease. In Uganda, women often have been blamed for the death of their husbands from HIV/AIDS. Rejection of HIV positive women by husbands and wider family members has been also reported as common. For example, in Uganda husbands who infected them may abandon women living with virus. The same practice was reported in India where women have been pushed out of their home and sent back to their family or village of origin. Some have been even beaten to death (104).

From studies on household and community responses to HIV/AIDS in developing countries, it was also reported that sero-positive women are likely to be treated differently from men. Whereas men are likely to be excused for the behaviour that resulted in the infection women are not (104).

In Ethiopia also women living with HIV/AIDS are stigmatised, ostracised and discriminated (105). There is no study done in Ethiopia to compare the level and the severity of stigma encountered by men and women living with HIV/AIDS. However, considering their lack of social, economic and political power and the existing moral

double standards on their sexuality, it becomes evident that women face more stigma than men.

As discussed earlier, stigma represents the construction of deviation from ideal expectation, which is culture specific. Hence, the stigma the women in this study encountered was a reflection of the ideal expectations of a moral woman; her responsibilities and accountabilities according to her gender and marital status in the Ethiopia cultural context.

### ***Double blame***

*... what were you thinking when you go out dressing such a short dress? It was your responsibility to cover your body and prevent this from happening. Men have this sexual urge and they can not help it. If you had covered up your self none of this could have happened...*

[Etalem a 19 year old unmarried girl and rape victim living with her parents.]

The words of Etalem, when she expressed her father's immediate reaction following the disclosure of her seropositive status to the family reflects the double blame and the severity of stigma women face even living in a situation where they have no power or means to protect themselves from rape and abduction.

The double blame some of the women faced was not only for failing to protect themselves from the infection, it was also for failing to practice the moral guardian role for the believed natural and uncontrollable sexual urge of men.

*... look how they are dressed .How could a man stop thinking about having sex with each one of them when they make themselves so tempting? They called the problem on*

*themselves. So I do not have sympathy for women who got raped and became infected with HIV these days. They have no manners at all.*

[Almaz a 53 year old woman participant of the exhibition talking about young girls in the exhibition who wore short dresses.]

These double blames and stigmatisations of the women in both examples is the reflection of the norms that put double moral standard that make women more accountable for sexual relationships than men and thereby make them more stigmatised than men. The moral guardian role of women and their responsibility for controlling the uncontrollable natural sexual desire of men was mentioned in many interactions both with members of Tesfa Ggoh's community and in public forum

Marital status was also another reason for the double blame some of the women in this study encountered.

*... it is difficult for those of us who are not married. If you have AIDS after you are married it is not only you who will take the blame because people might also think that you could be an innocent victim and your husband might have brought the disease. So, the blame is worth for those of us who are not married.*

[Martha a 20 year old unmarried girl.]

Almost all women who participated in the study acknowledged experience of stigma and discrimination in one or another way, irrespective of their marital status. However, the severity and the complicated nature of the stigma they encountered varied between those who are or had been married and those who were never married.

In a society like Ethiopia where marriage is universal and premarital sex is unacceptable for a girl, violation of the norm of premarital sexual abstinence by itself causes blame and stigma. The additional presence of HIV, which is often considered the sign of immorality, might have made the blame and stigma of some of the women double.

*...when I disclosed my status to my family my father said, "You are a girl, you were not supposed to have sex before you get married. If you had not done this bad thing in the first place you would not have brought shame on yourself and us."*

[Aberu, describing the reaction of her father when she first disclosed her sero-status]

The severity of the blame and stigma on never married girls is the reflection of the existing sexual double standard in Ethiopia. Most women who got HIV/AIDS before they got married shared Aberu's experience and the blame they encountered was double.

Due to the lesser severity of stigma encountered by married women compared to unmarried ones, changing marital status and pretending to be married was used as a blame reduction strategy.

*...first I used to tell people my true marital status; single and never married. I saw their disrespect in the way most of them treated me including health professionals. So I have changed my profile to a widow, who was married to a truck driver, who gave birth to two kids. After I created my new profile they started seeing me as a victim and treating me with respect...*

[Elizabeth explaining how she managed to get respects and better treatment by changing her marital status in health institutions.]

The strategy used by some women like Elisabeth to minimise the double blame and differential treatment they faced by changing their marital status in specific places indirectly shows the difference in the level of stigma that never married women and married women or women who had been once married face. However, it is clear that such a strategy is a very limited temporary solution, applicable to limited places and circumstances, where other people do not know about their marital status. Hence, such a strategy is not applicable to their community where people know them. The way the unmarried girls described their attempts to minimise stigma as a stigma *reduction* but not *avoidance* strategy also reflects that married women are not exempted from being stigmatised but at least they get sympathy.

*...When people knew my serostatus most felt sorry for me and said, It must be the husband who brought the disease to her” while some said, She could be the one who infected him.”*

[Tirunesh, a 26 year old widow and a mother of 2 children.]

However, even though being married lifts the layer of stigma that results from practising premarital sex, married women also have another issue that makes the blame double.

*...Even though I am the victim of his extramarital sexual affairs, my husband’s relatives put the blame on me. They said, “A husband who has a wife who satisfies his needs will never look into another woman.”They think it is my failure to be a good wife that lead him to extramarital affairs and exposed as to the infection.*

[Bekelu, a 42 year old married woman expressing her experience of double blame.]

Another reason for the double blame and stigma some of the women encountered was being a young woman and belonging to the younger generation.

### ***Yezare Zemen lijoch***

*...We used to listen to our parent’s advice and obey it. We never got involved with boys. That is why we have kept our family name up and did not bring shame in to our families. Yezare zemen lijoch they do not listen...*

[A grandmother who came to Tesfa Goh in search of support for her 3 years old grand daughter who lost her only parent (mother) due to AIDS.]

Yezare zemen lijoch is a term used to refer to the young generation. Another factor that contributed to the blame of the HIV infected women was belonging to the younger generation.

Young people are not considered capable of making independent decision and they are expected to accept their parent’s and other older family member’s decision about their life including their sexual life. But compared to women, young men have more

freedom to make decisions in their lives. Young girls more often are considered weak and are not allowed to make independent decision especially concerning their sexual life. Their decisions are more often evaluated in relation to their family's reputation and they are taken to be reflections of the moral fabric of their family.

In addition to the generational blame they face for belonging to the young generation, which is often taken to be responsible for the AIDS epidemic, the double standards set on their sexuality makes the blame of the younger girls worth

*... we are taken to be responsible for the epidemic due to the believed immoral sexual life we are leading. Whichever way you get the disease, nobody believes your story if you are young and unmarried, especially a girl. It is as if being young is committing a crime...*

[Genet a 19 year old unmarried girl.]

## **6.2 Effects of HIV/AIDS related stigma**

### **6.2.1 Categorical treatment**

*...whichever way you got the disease it is all the same. They could not think that we could have different behaviours as different individuals. If you have HIV you are immoral. It is common here to hear people saying, "I thought she was a descent girl how come she got AIDS?" Once you are diagnosed and people find out about it, then you are put in a category of the indecent, the category of the immoral...*

[Zenebu a 26 years old divorced women.]

One of the consequences of stigma that the women found frustrating was the categorical treatment. The categorisation issue was a big challenge because it was something that they faced whenever and wherever the HIV/AIDS issue is mentioned.



The categorical treatment was experienced by the women in this study at different levels. For some like Zenebech, it was limited to their interpersonal relationship; for others it was at an institutional level. Most women in this study have different experiences in different institutions.

*...there is no way that you could escape from categorisation and differential treatment. It is there even in holly water places. Whichever way you get the disease they tell you that you need especial prayer to be cured. They have especial sessions for people living with HIV/AIDS.*

[Alemitu a 28year old unmarried woman explaining her experience of categorical treatment in holly water places.]

More than half the women in this study tried faith based healing and were unhappy with the categorical treatment. The categorical treatment in faith based healing was a major cause of frustration for the women because for them, in faith based healing, where no health condition is beyond cure, the need for categorising and conducting special session was a reflection of the shared understanding of the infection with sin and immoral behaviour.

For some of the women in this study the categorical treatment experiences were in health institutions.

*... I can see the difference in the way my doctor treated me after I told him that I have HIV. I am not an individual patient any more I am just one of those HIV cases. He starts writing prescription even before I finish telling him my complaints.*

[Zahara a 19 year old unmarried girl talking about her experience in a hospital setting.]

The experience of categorical treatment in health institution settings may reflect the symbolic nature of HIV/AIDS stigma. Although more often stigma is believed to be associated with ignorance about HIV's mode of transmission and believed to decrease with better knowledge and understanding about it, at least in these settings it is clear that the cause of categorical treatment of HIV positive people is not related to fear of contagion.

Fear and experience of categorical and differential treatment in hospital settings where they haven't taken their HIV test and their serostatus is known forced some of the women to use a strategy to avoid such experience. The strategy was to move to a new setting and to start treatment without disclosing their serostatus. In this strategy used to avoid categorical treatment, although the focus of the women's effort is avoiding the categorical treatment, this strategy will have grave consequences on their health condition and contributes to shortening the lives of the women. This is so because hiding their serostatus will reduce their opportunity to get better diagnosis and appropriate treatment that put their HIV serostatus in to consideration.

In addition to the categorical treatment in different levels and settings, some of the women in this study were victims of the devaluating effects of HIV/AIDS related stigma.

### **6.2.2 Generalisations**

For some women in this study the effect of the HIV/AIDS related stigma was not limited to their sexual behaviour; it was also reflected in the way others valued their total moral personality.

*...when people who know my HIV status see me going to church I see the surprise in their face as if they have seen the devil in the church. The same is true when I tell*

*them that I am helping people who need home based care. When you have AIDS you are seen as a devil that hasn't got any good inside...*

[Fikir a 23 years old unmarried girl living with her brother.]

Like Fikir the major cause of frustration and depression for some of the women was the generalisation made about their total moral personality by inferring from the immoral sexual behaviour they are believed to have, and the stigma that follows it.

Such generalisations made about the total moral personality of the women affected by the virus manifested itself in many forms and had different kinds of effects and impacts on the women's lives.

One of the manifestations repeatedly mentioned by the women in this study was their downward mobility in the social hierarchy.

*...disclosure of my HIV status has taken away all the respect that I have in the family. They have allowed me to live with them. They feed me and buy me cloths but they don not value my opinion any more...*

[Elisabeth a 26 years old unmarried girl living with her parents.]

For some women like Elisabeth the devaluating effects of the resulting stigma were reflected in loss of respect they have encountered in their interpersonal relationships with family and close friends. The experience of others reflects the reductive effects of HIV/AIDS related stigma.

### **6.2.3 Reductive effects of HIV/AIDS stigma**

#### ***Becoming the Virus***

*... I was a respected teacher in my institute and used to have good relationship with my colleagues. I used to hear the appreciation's my students have for me when they*

*talk about me to their friends. They used to say, “Look! Here is our good chemistry teacher”. Now I do not hear those appreciations any more. If I hear students talking about me then it is about my HIV status. I heard them saying, “look this is the teacher who has AIDS” I can see the loss of respect in their face. I think all they see when they look at me is the virus; May be also the believed “immoral sexual behaviour” of me that caused me the syndrome. HIV has shadowed everything that was appreciated about me...*

[Ayelech a 35 year old widow and a mother of one child.]

The devaluating effects of HIV/AIDS related stigma that resulted from the generalisations made about the total personality of some of the women in this study affected the lives of some of them to the extent that they are reduced from a whole human being to a virus in the eyes of other people. It also shows how the virus took over their identity to the extent that people see them through the virus alone.

Ayelech's experience reflects the devaluating nature of stigma and the downward mobility it causes in the social hierarchy, which goes to the extent of shadowing even the strong and appreciated qualities of some of the women.

The effects of the immoral labelling and the devaluating effects of HIV/AIDS related stigma were not limited to the HIV positive women. On many occasions that I have mentioned the issue for discussion or listened to the conversation of women with an unknown seostaus *encountered* during the study, it was described as the mains cause of dilemma whether to take the HIV test or not.

*...I know how difficult it is for women who know their positive serostatus some died from depression. The idea of knowing that you have incurable disease is enough to cause you depression. But they lost friends, their respect by their family and community due to their believed immoral behaviour that exposed them to infection. They became the topic of gossip for their neighbourhood. Even though I know the advantages of voluntary testing it is difficult for me to decide. I do not think I can handle the risk of such devaluation and social rejection...*

[Eskedar a 20 year old girl associate member of Tesfa Goh expressing her dilemma whether she should be tested or not.]

Eskedar's dilemma reflects how the devaluating effect of the stigma influence the decision of others to get HIV tested. Such dilemmas were reflected in different occasions by many of the participants who did not know their HIV serostatus encountered during the study period.

Another devaluating effect of stigma experienced by the women in this study was being considered as a threat to others and facing the social rejection that follows.

### ***Becoming the pollutant***

*...I was teaching about HIV/AIDS in the nearby school. When I went to visit my friend afterwards her mother said, "I want my child to have a friend who has sense of moral and responsibility. I am sure that you cannot be that friend. I do not want you to pollute her so please stop coming here..."*

[Beza a 23 year old never married girl expressing her experience following disclosure of her serostatus.]

Beyond being reduced to something inhuman, some of the women were considered pollutants. Their believed immorality was taken as if it is socially infectious and their friendship was taken as a threat to moral personality of others.

The experience of some of the women also reflects how much the devaluating effect of the HIV/AIDS related stigma was feared not only by HIV positive women but also by their families.

*...when my father heard my serostatus he said, "How could you do this and disgrace us? We brought you up properly. You studied the bible, which is the base of moral behaviour. I can not sit with community elders and advice on family matters any more. How can a person who could not control his daughter's behaviour advise others what to do with their family?"*

[Mihret a 19 year old unmarried girl expressing her father's fear of blame and his reaction.]

In Mihret's situation the reaction of the family could be explained in terms of fear of devaluating effects of stigma by association, which in Goffman's terms is called courtesy stigma (102). The feared devaluating effect of stigma by the family of the HIV positive women might also reflect that believed immorality that brought the disease on the women was considered not only as contaminant and socially infectious but also shared among family members.

In a country like Ethiopia where parents are the ones who take the first blame for the believed "wrongs" children do, courtesy stigma has broad implications and impacts on the families of the HIV infected women. First a child's behaviour is believed to reflect the behaviour of the family. Hence, when children do something considered wrong in their cultural context especially, when the believed wrong perpetuated is associated with moral issues, it triggers inquiry into the moral values of the parents and their ability to raise children. However, this is not equally applicable to a boy and a girl, especially when it has to do with sexual behaviour. As discussed earlier, since young girls are considered weak and are not considered capable of making independent decisions especially concerning their sexual life, parents are taken responsible for controlling it and help the girls make a moral decision. Second, since associations are commonly made between the moral personality of the women and the moral fabric of their families the immorality that the HIV infected women are believed to have is also believed to be shared by other family members who partake in the same family moral pool. Hence, the believed immorality of the women is shared and results in inquiring into the morality of the other family members.

Hence, the way Mihret's father blamed his daughter in this situation may also reflect the struggle in reclaiming the moral status of the family. It could also be interpreted as an attempt to preserve the integrity of his child by indicating that she is responsible even if it means blaming her for not respecting the moral rules.

*...when my older brother found out that I am HIV positive and I could not go abroad because of my serostatus he said, "You should be ashamed of yourself. How could you start the immigration process while you knew what you have been doing? Now it is going to come out in the open and every one will know that our sister has got AIDS".*

[Alemitu a 28 year old women, who learned her serostatus while undergoing medical check up for her travel to USA, talking about her brothers' reaction when she disclosed her serostatus.]

In addition to parents, other family member's were afraid of the possible devaluating effect of stigma and their reaction towards the women is the reflection of this fear. The reaction of Alemitu's brother could be due to fear of such stigma that may follow the believed presence of shared immorality among family members. For some family members of the women in this study the courtesy stigma was not enacted i.e. actually encountered in discriminatory acts, it was rather felt. In Scramblers terms the

families' reaction is a reflection of one of the referents of *felt* stigma; that is, fear of possible stigma that follows others finding about it (106). *Enacted* stigma refers to the actual experience of stigma (106). For some of the women in the study and their families the stigma was felt rather than enacted stigma by courtesy.

The effects of the devaluating effects of the stigma the women encountered were not limited to their interpersonal relationship and the way other people evaluate their moral personality. It was also reflected in their intrapersonal dialogue and in the way they evaluated themselves.

## ***Self blame***

*...He is right I am a girl not a boy. So I should have abstained from sex until marriage. I should not have done this immoral thing...*

[Aberu's response when she was asked what she felt about her father's reaction. ]

Another reflection of the devaluating effects of stigma for some of the women in this study was negative evaluation of self and consequently self blame. However, the way some of the girls felt guilty and blamed themselves for breaking the sexual norms of their religion and culture as Aberu did might be the intrapersonal reflection that the sexual moral values that made the girls stigmatised are not only values of those who stigmatise them but also shared by the stigmatised.

This shared understanding and association that lead the women to self blame are the results of the double moral standard that HIV positive women share with people who stigmatise them as members of the same society.

*...I got the disease because I sinned. Maybe I deserved to be treated like that. I know that as unmarried girl, I was not supposed to have sex before marriage neither my religion nor my culture would approve it. But sometimes it becomes hard, I know that God has forgiven me; I wish people could do the same thing...*

[Alemash a 26 year old unmarried girl blaming herself.]

Like Alemash, some women accepted the stigma they faced as something that they deserved especially when they believed that the disease is the result of the sin they have committed.

The way the women blamed themselves might reflect that the dominant values and double standard on women's sexuality that have been enforced and internalised through complex interlocking of cultural, religious and political forces on the women's lives are in operation. The internalised versions of these dominant moral values have been reflected in the experiences expressed by the HIV positive women in both intrapersonal and interpersonal levels, in the way they evaluated themselves and the way they commented on the stigma others encountered. The women's self blame without questioning the appropriateness of the double stigma also reflects how the moral values and double standards that lead to their stigmatisation operate without conscious recognition of the purpose of those values in producing and maintaining the existing gender inequality.

However, the women's self blame could also be a way to reclaim a degree of agency and to avoid passive role of victim (objects of the action and will of others), and gain a subject status however morally tainted. Such an attempt was also reflected when family members blamed some of the women. The consequences of HIV/AIDS related stigma and its devaluating effects, which followed the disclosure of one's status, affected the lives of the women in this study in many ways. The downward mobility and loss of status they have experienced was not limited to themselves. It was affecting their families as well. Fear of such effects was the cause for the dilemma of coming out.

## 6.4 The dilemma of coming out

*... As soon as the lady who rented me a room heard the news about my HIV positive status, she asked me to move out immediately. She did not give me even a day to find another place to live. I had no where to go so I was forced to spend nights in the church yard until I managed to get a house very far away from my previous neighbourhood...*

[Shitaye, expressing the incidence that followed disclosure of her serostatus in public.]

Though as discussed above the consequences of disclosing one's serostatus makes and has the potential to make the lives of the women complicated, coming out or disclosing ones status is among the encouraged public health HIV prevention measures to "give face" to the epidemic. In the interviews and discussions I have encountered both with individuals and in group experiences of social rejection that followed other women's disclosure of their HIV status was very much feared by those who did not disclose their serostatus.

*...I have seen what happened to people who have disclosed their serostatus so I keep on asking my self if it is worth doing it...*

[Martha a 20 year old HIV positive girl who did not disclose her HIV positive serosatus yet, talking about her dilemma of coming out.]

The consequences of coming out that they have learnt from the experience of other and the fear of encountering the same problem themselves were among the reasons that put some of the women who had not yet disclosed their serostatus in dilemma.



For others the dilemma was the result of the broader effect of stigma that might follow disclosure of their serostatus to their family. This is because disclosing their status means exposing not only themselves but also their family to courtesy stigma, since their immorality that they are more often believed to have is considered as if it is shared among family members.

The consequences of HIV/AIDS stigma that resulted from the association made between the infection and the moral personality of the affected women as discussed above made the lives of the women and their family difficult. Hence different coping strategies were used by the women in this study in an attempt to protect themselves and others from stigma and to reclaim the moral integrity of their families and themselves.

## Chapter VII

### Coping with HIV/AIDS related stigma: pursuing safety

Different coping mechanisms and strategies were used by the women in this study to avoid stigma and blame to themselves and to their family resulting from the moral infection they are believed have and their believed shared immorality. One of the coping mechanisms used was to detach themselves from the category of the *immoral* and attributing the stigma to the *immoral others*.

#### 7.1 The immoral others

*... if people found out that you are HIV positive they automatically conclude that you belong to the category of people who have immoral sexual behaviour. So most people wouldn't believe that you do not have such behaviour...*

[Tsehay a 32 year old unmarried woman.]

Tsehay's anger and frustration was shared by most women. As mentioned in the earlier discussion with other women, as well as in the discussions about risk group and moral category issues, HIV/ AIDS infection is associated with special category of people, who have immoral behaviour. Such associations were also reflected by the HIV infected women, when they attempted to detach themselves from such group and thereby reclaim their moral integrity.

*... It is difficult for people to realise that people living with HIV/AIDS could be victims like me. They could not see behavioural the difference that exists between us. The moment they knew our serostatus they put us together with the promiscuous, the indecent or the immoral. Even a person who sticks to one partner like me could have HIV/AIDS. But once you have AIDS you are considered one of them [the immoral]...*

[ Birke a 20 year old unmarried girl.]

The reaction of the women like Birke might be due to blame and stigma they faced while being innocent victims of husband's or boyfriend's multiple sexual relationships. However, the women's effort might also be a coping strategy in an attempt to reclaim their moral integrity by detaching themselves from the category of the immoral others. By doing so they may be able to defend themselves from the labelling and stigma coming from others due to the believed immorality of HIV infected women in their interpersonal relationships. But it could also help to minimise the negative feeling that they develop towards themselves and the self-blame that might follow.

Although it was used as a coping strategy by HIV infected women, the category of the *immoral others* was repeatedly encountered during the study period both with people living with the virus and participants of this study who did not know their sero status irrespective of gender difference. This might show that HIV/AIDS is not seen as a mass phenomenon as it should be but rather taken as a syndrome affecting a category of people with a weak moral fabric.

Following the discussions about the association of HIV with immorality, people who did not know their serostatus but are participants of the study were interacted with outside the interview core group during the study period. They were asked whether they think that they could be at risk of HIV infection. Responding to the question, despite their knowledge of possible exposure that might have exposed them to HIV infection, most said that they do not think that they are at HIV risk. This may not be, however, due to failure to perceive HIV risk since they clearly knew how the disease is transmitted and even mentioned individual experiences that might expose them to infection. It could rather be due to fear of social risk that might follow admitting that

one is at risk of HIV and thereby admitting that one belongs to the category of the immoral which has adverse effects to oneself as well as to one's family.

Most women in this study did not question whether the association of the infection with moral disorder and the immoral labelling is appropriate. Neither did they inquire whether such category existed. Rather the effort was showing that they do not belong there.

Beyond coping strategy, however, this also shows that associating HIV/AIDS with immoral behaviour and attributing it to the immoral other is not limited to people who are/or consider themselves sero-negative but it is shared with HIV positive women too. This shared understanding and association could be explained in terms of the norms and values HIV positive women share with people who stigmatise them as members of the same society.

Another coping strategy used by some of the women in this study who found the consequences of coming out too risky to themselves and their family was silence.

## **7.2 Silence**

*...I have learnt my lesson. I have been forced to leave my house that I have lived-in for ten years and lost my friends because I have disclosed my status. I moved far away to a place where there is no one who knows about my serostatus. Now I know that the only way that can protect me from stigma and discrimination is silence...*

[Yeshiwork explaining her decision to keep her serostatus silent in her new environment.]

Although potentially at odds with the HIV prevention messages that encourages disclosing serostatus, silence was used consciously by some of the women in this study to delay or shorten the duration of stigma to themselves and their family. For

some of the women like Yeshiwork, the conscious silence strategy was employed following their experience of stigma. For others it was devised based on the experience of others.

*...I know what had happened to my friends who disclosed their status and how hard life became for them after that. I do not want anybody to know about it. That way I will be safe at least until I start showing symptoms and I can not hide it any more...*

[ Aselefech a 36 yeas old widow.]

For some women like Aselefech, the decision they made to keep their status silent was not the result of the stigma and discrimination they have *encountered* it was rather the result of *felt stigma*.

Some of the women in this study explained the conscious silence strategy as a way to hide the attribute that made them different i.e. their HIV positive serostatus and thereby reduce or delay stigmatisation at least temporarily.

*... You can see me. Nobody knows my serostaus so I am not stigmatised. People can not treat me differently unless they know that I am different. So why should I take the risk? As long as I am healthy and can keep my serostatus silent I am not different from them and I do not have to worry about being stigmatised...*

[Genet a19 year old unmarried girl.]

As Goffman described it, stigma rests on difference (102). However a mere presence of a difference does not cause stigma unless it is recognised by others. Therefore silence was used by some of the women like Genet as a way of hiding the difference, that is, their HIV status that causes stigmatisation. For these women even though temporary, silence was the only way to avoid the immoral labelling and devaluating effects of stigma that might follow disclosure of their serostatus. Hence, hiding the difference by keeping their serostatus silent is a matter of staying in power and maintaining the existing power balance between them and people that might stigmatise them if they knew their serostaus and thereby maintaining their status and the status of their family in the social hierarchy.

The purpose of the conscious silence strategy was to avoid stigma and its devaluating effects however the levels of silence varied among the women in this study.

*... I am not proud of the disease that I have. I most of the time feel ashamed of my self. I do not know how long I can be healthy enough for people not to recognise that I have AIDS. But until it becomes impossible to hide, I will keep it to myself. I would not*

*discuss it even with my mother because I want her to continue respecting me in the way she does now. Thinking about the discrimination and the blame terrifies me.*

[Desta, a 22 year old unmarried girl living with her mother talking about her felt stigma and her decision to protect herself and her mother by keeping her serostatus silent.]

Desta's decision to keep her serostatus secret even if she knew that it is a temporary solution was an effort to protect herself and her mother from the possible consequences that follow disclosure of her serostatus.

Some of the women who shared Desta's decision kept their serostatus silent to themselves whereas others kept it secret at a family level.

*...When I disclosed my status to my mother, she asked me to give her the paper that shows my HIV status. She took it and locked it in her box and we promised each other to keep it silent between us...*

[Elisabeth describing how she and her mother decided to keep her status silent between family members.]

Elisabeth's situation shows the level of silence where the HIV infected individual and her family agrees to keep the serostatus silent from public discourse in order to avoid stigmatisation of the infected person as well as the family.

Although in most cases silence was agreed upon in the family after discussion, in some cases silence was agreed upon *in silence*; experienced but not articulated.

*...I took the blood test to go to Saudi Arabia and work as a housemaid. When the test became positive and I found out that I am infected I kept it quiet. A week later my aunt, whom I am leaving with, asked me if I have changed my mind about going*

*abroad and I told her that I could not go. I know that she understood what I meant when I said I could not go but she never asked and I have never talked about it...*

[Tinbit describing the silent agreement made between her and her aunt to avoid further discussion of her HIV serostatus.]

The kind of silence Tinbit's and some of the women who shared the same experience had could be described as negotiated silence. Such silence results from a situation where two or more parties do not want to openly acknowledge that they know something about the other party and avoid discussion of the issue, although the party in question knows that they do. Silence in this case, although not verbally negotiated, implies a common agreement to avoid discussion and communication on the issue. Such silence here serves as a temporary solution to avoid the reaction of their family and minimise the stigmatisation of oneself and family members.

HIV/AIDS stigma as a social control mechanism and as a social process works through individuals in a given cultural setting, who share more or less similar moral values and norms and react whenever the moral norms are violated. It is this collective effort of individuals in a society that makes maintenance of the existing social moral order possible. Hence, from this it can be derived as there is certain predictability in how people will react when norms are violated. The aunt's silence instead of further inquiry about the test results makes her free from acting in the manner she was supposed to act against PLWHA, whose health problem is believed to symbolise immorality, in her cultural context. It also helps her to protect her niece by avoiding the possible and expected reaction she would have towards Tinbit if she for sure knew her HIV positive serostatus. Hence, avoidance of the issue gives temporary solution for both women. The aunt will have a chance to continue living with Tinbit in

the way she used to. It is useful for Tinbit also because as long as they have agreed, in silence, to silence the issue, she does not need to worry about what would happen if her aunt finds out. She knows that she aunt also knows.

Silence was a coping mechanism agreed upon and used by many of the women in this study at different levels to avoid stigma and its totalizing effects that result in loss of status in their society. However, it is clear that, be it in whatever level, the silence strategy of the women used was the result of the power of dominant discourses that ignore the difficulties and challenges the women encounter in protecting themselves as individual members of society and make expressing their individual even unique situation and experience unacceptable and hence silence their voices.

Although the conscious silence strategy was used by some of the women in this study to avoid stigma and its consequences, it was not found to be adequate solution by itself. There are multiple reasons for this. The first reason could be the temporary nature of the protection. Since keeping their serostatus silent is possible only in the asymptomatic phases of the syndrome's trajectory, silencing ones status would not be possible ones they have full-blown AIDS. Another possible reason might be the stress created by the emotionally exhausting effort required for hiding one's status on a daily basis. A third reason that might have made the silence strategy inadequate to cope with HIV/AIDS stigma was the consequences of stigma which changed the life of the women from productive to dependent citizens and made them dependent on the economic support of others. Hence another coping mechanism used by the women in this study was Joining Tesfa Goh.

### **7.3 Joining TesfaGoh**



*...I am tired of being reminded that I am different and being judged. Here in Tesfa Goh there is no one to blame you, judge you or to remind you that you are different. Here I have friends who have the same problem like me, who can share my problems and fears with out judging me...*

[Firehiwot a 26 year old unmarried woman who explaining her reasons for joining Tesfa Goh.]

HIV positive Women in this study joined Tesfa Goh for different reasons. For some of the women in this study like Firehiwot the reason for joining Tesfa Goh was the need for a place where they can be free from being judged for their believed irresponsibility and immorality.

For some women it was finding comfort and guaranteed friendship, which does not depend on serostatus.

*...the safety of the relationship that I have with my other friends and my acceptability is guaranteed as far as they do not know my status. If they knew about my status then I know that things would automatically change. When friends who know nothing about my serostatus hug me and kiss me I think how different it would have been if they knew my serostatus. Here I do not have such worry. People who hug me here know my status and I do not have to worry about losing their friendship...*

[Marta 21 year old unmarried girl explaining her guaranteed friendship with fellow members of Tesfa Goh.]

For others the reason for joining Tesfa Goh was getting tired of hiding themselves and the need for friends who are in the same situation to share their problems with.

*...you get tired of silence. You get tired of lying. You need someone to tell the truth about your condition. Its risky to try to share it with other people because you do not know how they would react but here it is a shard problem so it is safe and easy...*

[Zinash a 34 year old widow.]

For some women in this study joining Tesfa Goh was the only option not only to cope with the immoral labelling and avoid social rejection but also to deal with consequences of sigma and to stay alive.

*... I heard about voluntary counselling and testing and took the test and found out that I am positive. I disclosed my serostaus in public believing that I could save others. Before this I used to earn money by cleaning houses and washing clothes for customers. Following disclosure of my status all my customers told me that they do not want my work any more. I have tried hard but in a small community where almost everybody knows everybody, it was not possible to find someone who has not heard about my HIV infection. Consequently I could not get the chance to work and support myself. Although I am healthy and capable of working and supporting my family, I was forced to look for financial support. That is why I joined Tesfa Goh.*

[Wubet expressing her reason's for joining Tesfa Goh.]

Another acknowledged reason given by the HIV positive women for joining Tesfa Goh was taking part in the HIV prevention efforts and the fight against HIV/AIDS related stigma. Some women in this study considered joining Tesfa Goh and participating in the activities as their duty and responsibility in the fight towards HIV/AIDS related stigma and this was their main reason for joining Tesfa Goh.

*... It is not easy to go out in public and disclose your status. You have got a lot to loose but we do it to save lives. Even without disclosing their status our sisters who were seen coming out of TesfaGohs's office faced a lot of problem and have been displaced from their homes. We came out even though we knew the risk of social rejection that follows disclosure of our status. Because some one has to do it or else the infection and the stigma will continue...*

[Yordanos a 32 year old married woman.]

For some women the purpose of joining Tesfa Goh's community was more than getting friendship; sharing their fears and worries and getting support from the organisation's community. It was mainly described as part of their contribution for the collective effort of the organisation's community in the construction of a new moral identity of HIV infected individuals by changing their projected immoral identity and thereby redefining their position in society.

*...Being here and participating in the activities gives me a chance to show that HIV positive people have moral too. I have sacrificed a lot when I disclosed my status to save others. My colleagues are doing the same thing. Maybe some day people will realise how much we care about them and the good that there is inside us...*

[Abinet describing why she became member of Tesfa Goh.]

The encouraging effects of the effort to change the projected identity of HIV positive people and redefine their position in society were reflected in many ways during the study period.

*You are the heroes of the century!*

*God bless you for the effort that you are making to save the generation!*

The above statements were taken from notes of complement written to Tesfa Goh community in the visitor's book prepared for the participant's of the *Zimitaw yiseber* (Let us break the silence) exhibition in which Tesfa Goh participated. This might reflect that they were able to influence the attitude of people towards HIV positive people at least to a certain extent. It is also interesting to observe how people stigmatised as individuals were able to project a moral identity and influence the attitude of people towards people living with HIV/AIDS by organising themselves in to a community to the extent that they are considered heroes.

Through participation in such collective efforts of the Tesfa Goh's community, some of the women in this study were able to re-evaluate their negative feeling towards themselves and cope with the devaluating effects of stigma.

*.... Being here gives meaning to my life. Here I have no time to sit and wait for my death as I am expected to or tell myself that I am worthless as I have been told by my family so many times. There are lots of things that I could do to help others and this makes me feel good and alive. It makes me realise that maybe my life has a purpose...*

[Biruk, a 22 year old unmarried girl and a mother of one child.]

Participating in the effort to redefine their position in society and change their projected identity, some women like Biruk were able to re-evaluate the value that they have given to themselves and reconstruct the distorted meaning of their life by the devaluating effect of the stigma they have experienced.

## **Chapter VII**

### **Concluding remarks**

This study was motivated by the need to understand the reasons for the increased vulnerability of women to HIV/AIDS in Ethiopia. The original objective of this study was to acquire knowledge about phenomena that might contribute to increased vulnerability of Ethiopian women for HIV/ AIDS, by exploring moral scripts that might create possible dilemmas that might arise while women try to protect themselves and others from HIV infection and also meet cultural expectations of what it is to be a moral woman. The original plan was to investigate such phenomena by studying what happened in the lives of the women before they became infected. However during the data collection process it became clear that what happened in the women's lives after they become infected is equally important in understanding the phenomena that might fuel the epidemic and thereby contribute to increased vulnerability of women. Hence HIVAIDS related stigma and coping mechanisms which reflect what happened in the lives of the women after they became infected became integral to the study.

Different studies conducted in Ethiopian have shown the persistence of risky sexual behaviours along with high level of knowledge in the vulnerable groups. The persistence of such behaviour despite the possession of HIV related knowledge is explained by these studies in terms of individual failure to perceive the risk associated with unsafe sex practices. Hence, unsafe sex is reduced to the question of perception.

This study started out with two assumptions. The **first** assumption is that sexual risk is not something that can be avoided by singular individual because it is inescapably embedded in relations. The **second** assumption is that sex does not happen outside culture and power relations. Consequently, failure to practice “safe sex” should be investigated with respect to HIV/AIDS; in relation to power relations and the broader socio-cultural concerns and meanings that structure sexual *practices* within the collective flow of life.

Hence, it was important for the study to approach the field ethnographically. The result of this investigation is partly presented in the discussion (chapters 5, 6, & 7) and partly through the constructed ethnographic case (chapter 4). The case was constructed by the use of multiple sources and aims at an ethnographic description of some of the silent features of every day contexts, which the majority of Ethiopian women share regardless of their ethnic and religious backgrounds.

The discussion of the findings in this thesis has been organised around **two** themes which both revolve around conflicts and dilemmas. The **first theme** is about conflicts that emerged from *first*, general cultural moral codes guiding and governing interpersonal relationships such as child to parent obedience. *Second*, gender specific moral scripts that describe a woman’s moral worth in terms of her tolerance of abuse and her meaning of life in terms of the sacrifices she makes for the betterment of others, and *third*, public health prescription of avoiding sexual risk.

In the lived lives of the women the culturally proscribed behaviours were to a large extent not compatible with the behaviour proscribed by public health sexual risk avoidance message. In fact, in the lives of the women met in this study these prescriptions and messages were more often than not contradictory. These contradictions caused dilemmas about whether to follow what was prescribed by

public health efforts to avoid risk of HIV infection, or to accept the moral codes and scripts and avoid risk of social rejection. Since in the real life of the women to practise both often turned out to be impossible, choosing one over the other became inevitable. The reflected or unreflected decisions the women made and that exposed them to the infection, however, were not always the result of choosing to obey the general moral codes or gender specific scripts over the public health “safe sex” prescription. Their decisions were equally compromised by the existing institutionalised relations of power and privilege including the legal system that are organised around gender difference. Importantly some of the women even did not consider it as making a choice but as just doing the right thing. I want to underline here that by “decision” I do not mean conscious choices.

The **second theme** is about dilemmas that arise in practising “safe sex” due to the association made between “safe sex” and immoral behaviour. This is found in religious explanations given about the cause and purpose of HIV pandemic; in the unfortunate coinciding of the epidemiologically identified high risk sexual behaviour with socio-culturally disapproved and stigmatised sexual practice; in the language and words used to express the heterosexual mode of transmission in Ethiopia and lastly in the placing of condom at the bottom of the morally charged hierarchy of the ABC’s of HIV prevention messages. With this understanding, practising “safe sex” easily becomes associated with immoral behaviour. Hence, for example suggesting or accepting condom use suggestion conveyed a meaning different from utilising a simple HIV prevention device and taken to imply either accepting as one has immoral sexual behaviour or as implying a partner has immoral sexual behaviour. Due to this association both women and men were caught up in explicit and implicit dilemmas about whether or not to practice the prescribed “safe sex”. Dilemmas emerge when

accepting and practicing “safe sex” might be taken to contain a suggestion that they have behaved immorally. As I have discussed, there will be cases where the danger of being taken as one who puts forward such a suggestion is more feared than exposing oneself to the potential danger of HIV infection.

As I have shown in the constructed case and through the discussion the conflict of ideas and dilemmas the women faced continued even after they became infected because of the HIV/AIDS related stigma. Among the main factors that contributed to the stigma experienced by the women, the following were the major ones. First, stigma rest on the association made between HIV/AIDS and immoral sexual behaviour, hence, the HIV serostatus of the women was attributed to their having practised immoral sexual behaviour. Second, based on the sole information about the women’s serostatus generalisations are made with regard to their total moral personality. This was not limited to the women but also led to questioning of the moral fabric of their whole family. Third, the HIV positive women were taken to have an immorality that is infectious. Hence, for their friends and the families of their friends to maintain relationship became hazardous. Fourth, they faced double blame for not having moral sexual behaviour and failing to play the moral guardian role for uncontrollable sexual desire of men; for not complying with their gender script of remaining virgin until married and for being infected with HIV. Fifth and lastly, the devaluating effects of stigma they have learnt from the experience of those women who disclosed their serostatus and their families and from their own experiences; reinforced the dilemmas to the women.

When it comes to making a decision about whether to disclose one’s serostatus, the HIV infected women faced critical dilemmas. For example, following public health messages which call for HIV-positive persons to disclose their status, would easily



involve exposing not only oneself but also one's family to the devaluating effects of HIV/AIDS stigma. A less hazardous and viable choice would then be to continue to lead seemingly normal life keeping one's status silent until it becomes impossible to hide. By choosing such a solution the risk of social rejection was temporarily avoided. It should not be forgotten that, beyond risk of social rejection, in a country like Ethiopia where the only social security system is the extended family system, losing one's family support by exposing one's status which also "spoils" the family name could also mean losing one's only means of survival. These dilemmas were the reasons for choosing the *silence* coping strategy though it is contradictory to the public health message. This silence fuels the pandemic and in turn contributes to increased vulnerability of women.

To sum up, this study has found and shown that "safe sex" in the context of HIV/AIDS is not a risk free phenomenon. As I have described and discussed it, "safe sex" is rather a phenomenon situated amongst a range of issues pertaining to safety and danger in a given culture. Consequently, reasons for continuing to take sexual risk despite knowledge about the dangers involved and how to avoid them should not be investigated only with respect to HIV/AIDS but also in relation to the broader socio-cultural concerns and meanings that structure sexual practices within the collective flow of life.

As an ethnographic inquiry, this study of the experiences of the HIV positive women operates at micro-level. Even if findings from such a study may assist in shedding light on a more general level, additional studies in other contexts and realities are needed in order to investigate more fully what is shared and what differs across contexts. Further ethnographic studies in different settings may complement the

findings of this study and thus deepen our understanding of what is at stake when culturally proscribed behaviour trumps public health messages.

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## **Annex 1**

### **Request for participation**

Introduction my name is Meselu Taye and I have been working with people living with HIV/AIDS. Currently I am studying International community health in Norway and this research is part of the study. I am interviewing women members of Tesfa Goh Ethiopia in order to find out phenomena that might expose women to HIV risk. The findings of our discussion might get published and contribute to the fight against HIV/AIDS.

I would like to have discussion with you about situations that might contribute to exposure of women to HIV infection and we may need to meet again to clarify issues that might arise from our discussion. Our discussion may come to focus on private matters but it is important that you know your identity will be treated with confidentiality and the information that you provide will be used solely for the purpose of the study.

Your name will not be written on this interview note or anywhere else and will never be used in connection with any of the information you tell me. You don not have to discuss issues that you do not want to and you may end this interview any time. If you want to withdraw for the study any time along the study process you will not be obliged to continue or give reasons for doing so.

Refusing to participate or withdrawing form the study along the process will not have any consequences on you. However the information that you provide during the discussions will help to understand the phenomena that might make women vulnerable to HIV risk

I would greatly appreciate your help in responding to this interview. If you have any questions or any thing that is not clear please feel free to ask

If you are clear with the information provided and agree to participate please sign on the consent form attached.

## **Annex 2**

### **Consent Form**

I the undersigned have been informed that the purpose of this research is to find out situations or phenomena that might expose women to HIV infection.

I have been informed that I am going to have discussion with the researcher about issues that might expose women to HIV infection and the research may come to focus on my private matters and the discussion might be repeated if there is a need to clarify issues that might arise from the discussion.

I have been also be informed that the information that I give will solely be used for this study and this get published but my identity will be treated with confidentiality and my name will not be used in connection with the information that I gave.

I have also been informed that I can refuse to discuss issues that I don't want to discuss and can stop the interview any time I want and that I will not be obliged to continue the study or give reasons for doing so.

I have been also informed that I can stop participating anytime along the study process and as refusing to participate or withdrawing form the study will not have any consequences on me.

I agree to participate in this research voluntarily in the hope of contributing to understand phenomena that might expose women to HIV infection and the fight against HIV/AIDS.

Signature -----

Date -----

### **Annex 3**

This interview guide consists of semi structured open ended questions in the sense that the interview is conducted according to a list of items/ issues to be covered. The sequencing of the issues will depend on the flow of each interview questions so also to allow for follow up and exploration of relevant issues that might emerge during the interview process. The following interview guide is tentative and open to revision. Since all the interviews will be conducted on HIV positive women biographical data will be inquired.

- Age
- Sex
- Education
- Marital status
- Eccupation
- Ethnic group
- Religion

**Items to be covered in relation to their knowledge about HIV/AIDS and risk perception before becoming infected and family reaction to their HIV status.**

- If they knew about HIV/AIDS and prevention methods before they become infected.
- Where they got the information from.
- If they felt that they could get HIV.
- Why or why not.
- If they knew what prevented them from practicing the prescribed “safe sex” practice.
- If they knew how they became infected.
- Their knowledge about sexual matters before starting sexual activity.
- How they communicated with their significant others and reactions and events that followed disclosure of their HIV status.

**Items to be covered in relation to understanding of safety, pleasure and danger with regard to sexual practices and relationships.**

- What sexual safety means to them.
- What do they say gives sexual pleasure.
- What they think is dangerous to sexual relationships.
- What they think is expected from a woman in sexual encounters.
- What they think is important for a man sexually.
- About sexual partners and relations they have before knowing their HIV status.

**Items to be covered in relation to HIV/AIDS susceptibility, vulnerability and candidacy.**

- What kind of people did they used to think will get HIV.
- If their views have changed.
- If so how they have changed their views.
- What other people say about it.

**Items to be covered in relation to moral issues and experiences of possible conflict in practicing the recommended safe sex.**

- Their perception of moral person.
- Their perception of a moral woman and her characteristics.
- Difficulties of living to these general moral person expectations and/or specific to women.

- What they managed and what they didn't in fulfilling these expectations.
- If they experienced circumstances where they were in dilemma whether to practice safe sex or not due to these concern.
- If felt forced physically, psychologically or culturally to have sexual intercourse.
- If they have faced conflict of ideas or interests.
- What the reason for the conflict of ideas and interests was.
- If they were ever exposed to competing interests and conflicts in relation to their sexual safety and safety of their relationships.
- If they faced with competing interests and conflicts in relation to risk associated with their sexual practice and risk of failing to fulfill the social expectations.
- What made it possible or impossible to resolve the conflict and practice the recommended "safe sex".
- How they managed to resolve if they managed to do so.

#### **Items to be covered in relation to stigmatization**

- If they faced stigmatization.
- If there were any religious or cultural influences on the process of stigmatization.
- What they perceive is the most common prejudice on HIV positive people.
- How they think stigmatization could be acted up on.
- How HIV positive people are portrayed in the media
- If they are they stigmatized or not.
- What they think about their future life for them and their immediate relatives.
- How they became members of Tesfa Goh and why.



